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# PSYCHIATRIC SURVIVOR PRIDE DAY: COMMUNITY ORGANIZING WITH PSYCHIATRIC SURVIVORS<sup>©</sup>

BY LILITH FINKLER\*

## I. INTRODUCTION<sup>1</sup>

Like women and the poor, psychiatric survivors<sup>2</sup> are an oppressed group in our society. Social norms often marginalize people whose behaviour is outside the general understanding of the status quo. Voices hidden in rocky crevices of misunderstood minds and tableaux of illusion frighten many. Psychiatric survivors live in marginalized settings such as hospitals, boarding homes, group homes, or even air grates. Many of us receive little beyond our disability cheque<sup>3</sup> which is often assigned to a third party for safe keeping. Often, we do not have even our own bodily integrity. We are forcibly treated with heavy doses of neuroleptic drugs or given electroshock which results in short or long term memory loss. Until the late 1970s, many of us endured lobotomies which surgically tampered with portions of our brains.

While many middle-class psychiatric survivors have not withstood such penury and psychic punishment, the majority of survivors in Parkdale have suffered silently for many years. Given the above mentioned factors, it is logical for organizing efforts in the Parkdale community and at Parkdale Community Legal Services (PCLS) to focus on psychiatric survivor issues.

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\* Community Legal Worker, Parkdale Community Legal Services. The author wishes to dedicate this article to the members of the Psychiatric Survivor Pride Day Committee who made Pride Day possible.

<sup>1</sup> In an effort to honour the perspective of members of the Psychiatric Survivor Pride Day Organizing Committee, portions of this document have been altered. I write this article in both trepidation and excitement, knowing that it offers an opportunity to incorporate both faith and despair. As both a community legal worker and a psychiatric survivor, I struggle to create a bridge between two worlds. This article is a plank on that journey.

<sup>2</sup> "Psychiatric survivor" describes anyone who is, or has been, an inpatient or an outpatient of a psychiatric institution. Some prefer the term "consumer" or "consumer/survivor."

<sup>3</sup> The Ontario Disability Support Program funded by the Ministry of Community and Social Services provides financial assistance to persons with disabilities who are unable to work.

As a community legal worker<sup>4</sup> at PCLS, I advocate on behalf of, and in conjunction with, other psychiatric survivors. I spend a great deal of time gauging the pulse of the community that I serve. By playing cards with patients in the mall<sup>5</sup> at Queen Street Mental Health Centre, sitting on park benches, or visiting tenants living in boarding homes, I hear stories first hand. This allows me to identify systemic issues, rather than work solely on a case-by-case basis.

It is crucial that we, as psychiatric survivors, assert our strength collectively. Many of the human rights violations that we endure such as forced treatment, restraints, or seclusion occur in isolation. Sharing our past with one another and determining our goals as a group contextualizes and politicizes our common experiences of oppression. We no longer blame ourselves for our suffering.

While some organizers have chosen to build groups consisting of agency staff, I wished to work directly with vulnerable adults. Many of us labelled by psychiatry have been told that we are not capable of contributing to society; that we should take our medication and stay out of the hospital if we can.<sup>6</sup>

I first thought of organizing a "Pride Day" because I wished to counter negative images of our community by providing examples of activities successfully organized by an autonomous group of "crazy" people. I believed that a well publicized and well attended "Pride Day" would help change the public image, as well as the self-image of the organizers.

Further, I wanted to share the skills I had acquired over the years with others. Establishing an agenda, facilitating a meeting, or using group decisionmaking tools such as consensus are skills many of us take for granted. Many psychiatric survivors, socially isolated and acted upon by the medical establishment, have not had access to these practices—Pride Day could help us learn.

Psychiatric survivors, like other oppressed groups, are a heterogeneous lot. In order to build a broad base of support, we need to share with one another openly, away from the scrutinizing gaze of our

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<sup>4</sup> I also teach mental health law, supervise students on their community work placements, write briefs, lobby and present workshops.

<sup>5</sup> The mall is an area of the hospital where current and former patients socialize.

<sup>6</sup> For example, I was labelled schizophrenic at the age of seventeen. The prognosis, relayed by staff of the Children's Aid Society, included an ongoing reliance on psychiatric medication and intermittent institutionalization.

“workers.” Many of us have internalized a value system that places us at the bottom of the social hierarchy.<sup>7</sup>

By organizing an autonomous psychiatric survivor group, I intended not only to validate our organizational abilities, but also to affirm the benefits of associating with one another rather than those who oppress us.

## II. THE PARKDALE COMMUNITY

Parkdale Community Legal Services is one of the few, if not the only, legal clinics that specifically organizes with survivors of the psychiatric system. The PCLS catchment area has a high concentration of ex-psychiatric patients as a result of our proximity to Queen Street Mental Health Centre (Queen Street). Queen Street, the largest psychiatric facility in Ontario, is located six blocks from our office. The hospital has over four hundred inpatients, more than two thousand outpatients, and a significant number of “undocumented residents”—homeless people—who live in the public areas of the hospital during the day and sleep in hiding at night.

There are approximately sixty-five licensed boarding homes and rooming houses serving the psychiatric survivor population in the Parkdale area. In addition, there are many unlicensed boarding homes. Each home provides “care” to about thirty-five residents. Parkdale also provides street space to an uncounted number of homeless individuals. According to various estimates, psychiatric survivors comprise about 48 per cent of the homeless population in Toronto.<sup>8</sup>

## III. WHAT IS PRIDE DAY?

Psychiatric Survivor Pride Day is an annual event organized by an autonomous group of psychiatric survivors. First held in 1993, the day has been both a vehicle for social protest and a time of community building. The Pride Day committee of 1997 hoped that the day would

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<sup>7</sup> For example, at a legal conference, one psychiatric survivor activist asked me why I sat at the table of survivors, rather than at the other tables of legal professionals. She said that she would rather have sat with professionals, but she felt that they would not accept her.

<sup>8</sup> United Way of Greater Toronto Homelessness Project Team, *Beyond Survival: Homelessness in Metro Toronto* (Toronto: United Way of Greater Toronto, 1997) at 15.

fight the stigma of "mental illness," provide an opportunity to share food and clothes, and strengthen the fragile bonds of our community.

Pride Day 1997 consisted of a variety of activities including entertainment, a series of workshops, a clothing swap, videos, and an information fair, as well as meals, and opportunities to socialize. Everything was free and open to the public, both survivors, and non-survivors.

The group organizing the first Pride Day decided on the name because of the commonality of oppression we experience with members of the gay and lesbian community. In addition, both the dis/ability and the black community have focused on pride as a method of mobilizing and energizing their members. We hoped that the same positive approach that had inspired other oppressed groups would also motivate our own community.

Of course, not everyone saw the connections between the oppression of psychiatric survivors and the oppression of gays and lesbians. Some people telephoned to determine whether Psychiatric Survivor Pride Day was the same as Gay Pride Day. "Are any homosexuals going to be there?" one person asked. I answered in the affirmative and the caller hung up. When I distributed our poster at Gay and Lesbian Pride Day, I also received negative responses. Some gays and lesbians did not want to be associated with "crazies" and felt that we were "stealing" their day. "Name your day something else. Don't name it after us!"

#### IV. ORGANIZATIONAL CHALLENGES

##### A. *Identifying*

While our chosen name certainly presented barriers to acceptance, the biggest challenge in organizing Pride Day was reaching our intended audience. Many survivors had no address, let alone a phone or fax so we could not simply mail an invitation. Individuals who did have access to phones often only had voice mail.<sup>9</sup>

Psychiatric survivors are both invisible and visible in the community. Some folks dance the characteristic "thorazine shuffle"<sup>10</sup>

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<sup>9</sup> Voice mail allows homeless people to pick up messages without having an actual phone.

<sup>10</sup> This phrase refers to a stiff gait and involuntary muscle movements, a result of tardive dyskinesia. Tardive dyskinesia is a side-effect of long term use of neuroleptic drugs.

and are easily noticed walking along the street. Others of us, not forced to take neuroleptic drugs, may blend in with our “normal” neighbours.

Because many of us can “pass”—we are viewed as non-survivors—we tend to hide our psychiatric history from others. We are afraid of losing our jobs, our friends, and/or our children. This invisibility makes it hard to reach out. When I was handing out leaflets to advertise Pride Day, passersby were sometimes offended when I gave them a leaflet that spoke of “mental illness.” They thought that I had found them out. “How did you know?” they asked. After a number of such inquiries, I deliberately distributed posters to every person in a given area so that no one felt singled out.

Even when I visited a boarding home where everyone had a psychiatric label, tenants would claim, “I’m not crazy. I’m not like you. I don’t want to be involved.” People who have spent years struggling with their emotional difficulties may want nothing to do with advertising their pride.

### *B. Advertising*

To advertise Pride Day, committee members went to subway stations between eight and nine in the morning. In choosing this time, we hoped to reach people on their way to work who would pass on the information to friends and family. We also went to local shopping centres, as many psychiatric survivors frequent local malls as a form of entertainment. People who are socially isolated want to be around others, especially on Sundays, when many public buildings are closed.

We rode the length of the Queen streetcar, running into friends and acquaintances in the movement willing to disseminate information in their neighbourhoods. This was especially crucial because many operators of boarding home “care” housing would not allow us to visit their tenants. Without conventional means of communication at our disposal, we had to rely on insiders for distribution.

Members of our group who were “regulars” at Queen Street Mental Health Centre verbally invited patients at the hospital. This was important because many psychiatric survivors on medication have blurred vision, making reading extremely difficult. Other survivors, like some other low-income people, are illiterate.

In addition to the enormous in-person outreach, one member of the committee organized a full week of programming at a local community radio station. Advertisements were also played by the station on an hourly basis leading up to the event.

Significantly, out of a total of 127<sup>11</sup> people who registered at the event, only six found out about Pride Day through announcements in local papers. Marginalized people are isolated from mainstream news. The overwhelming majority either received a leaflet or heard about it from someone they knew.

### *C. Decisionmaking Among the Organizing Committee*

As the facilitator, I decided to use consensus decisionmaking among the organizing committee. I believe that consensus allows more group input and builds a stronger organizational base. However, not all members of the committee agreed with me. Some felt that consensus was slow moving and detail oriented. As a consequence, a number of participants became bored and left the group. When these people were asked to contribute in a specific and time limited way, they willingly came back. By trying to include some members of the group, I alienated others.

Group members collectively established ground rules. Everyone agreed, for example, not to discriminate on the basis of sex, race, disability, sexual orientation, etc. This meant that racist, sexist, and other hurtful jokes were not permitted and that the group worked to accommodate its members' differences. For example, members who spoke would face the group so those who were hard of hearing could lip read. In order to accommodate ideological differences among the group, I incorporated "brainstorms" during the meetings, so that everyone would have an opportunity to make suggestions without being afraid of criticism from others. This met the needs of "consumers"—outpatients at local psychiatric facilities—who were afraid of being ostracized by more radical members of the group.

As the facilitator, I found it difficult to balance the needs of the members of the committee. Being both a participant and an organizer, I struggled to mix the needs of learner-activists with the needs of the participants attending the actual event. I wanted to teach consensus

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<sup>11</sup> Unfortunately, many participants personally known to the committee did not register. Some survivors are afraid to sign anything and consequently refused us. Others did not speak English and while interpreters were available, no translation of the registration or evaluation form had been done. Others did not sign in because they were homeless. As one man said, "Why be on a mailing list when my address is the street?"

Sometimes, even when people did have an address, they did not wish to divulge it. Some inhabitants of shelters or hospitals were ashamed to let others know of their status. Victims of abuse did not wish their abusers to be able to locate them.

building by example. At the same time, I had the advantage of more than twenty years of organizing experience. I am still learning how to share my insight without being overbearing. I did not want to have an undue influence in the decision-making process.

I learned a lot about mediating differences. Members of the committee fell into both camps within our movement—consumers and survivors. The survivors stated clearly that psychiatry was *the problem*, while consumers believed that the medication and their doctors alleviated their mental illness. This divergence of opinion was reflected in our work. Our leaflet, for example was a compromise between the two perspectives. In one column, we complained both of being involuntarily detained in a psychiatric institution and of being refused admission to a facility. This parallels the conflicting demands of our movement for social change: some protest the closure of hospital beds, while others demand that every psychiatric institution be dismantled.

Some members who considered me a “survivor” expressed frustration that I was taking a “consumer” point of view. I wanted to balance group dynamics and ensure that both factions felt safe to articulate their positions. I felt fortunate to be trusted by both sides.

#### D. *Setting the Program*

The day’s program was the focus of a great deal of discussion at our weekly meetings. Members of the committee initially wanted prominent psychiatric survivors to be keynote speakers on the day. I had suspected that celebrity psychiatric survivors would be unwilling to attend, especially as no payment was offered. Because I wanted this to be a learning experience for the group, I reserved judgment.

Because of the numerous cuts to social services,<sup>12</sup> I suggested that Pride Day incorporate a public protest or rally. Members of the group expressed opposition to this idea and insisted on a strictly celebratory affair. Some individuals were afraid that if their worker saw them at a demonstration, they would be considered healthy enough to work. They did not wish to jeopardize their disability cheques. Others were afraid to offend their worker or psychiatrist, or did not wish to be seen publicly as a psychiatric survivor because they were seeking employment. This, then, was the paradox: members of the committee

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<sup>12</sup> See “Cuts Spell Trouble for Mentally Ill” *The Toronto Star* (12 March, 1997) A22; “Union Attacks Wilson over Psychiatric Beds” *The Toronto Star* (19 April, 1997) A3; “Mental Care in Crisis, MDs Say” *The Toronto Star* (15 October, 1997) A2.



wanted others in our psychiatric survivor community to reclaim our status as ex-psychiatric patients, but we were not willing to do so ourselves. In some cases, the cost would have been too great.

When it became clear that the group was unwilling to sponsor a demonstration, I suggested a series of workshops instead. We agreed to four workshops which focused on: (a) tenants' rights; (b) policing issues for psychiatric survivors; (c) the closing of homeless drop-in centres; and (d) changes to family benefits legislation.<sup>13</sup>

I was concerned about running a social assistance workshop because I feared that speaking about pending changes would alarm social assistance recipients unnecessarily. A number of Parkdale's past clients had committed suicide after being informed of their difficult legal situations. Psychiatric survivors are already emotionally precarious—why add to their stress? At the same time, how can we mount an effective campaign of opposition if we are not fully aware of the political situation? I decided not to voice my concerns. Ultimately, the group's decision was the right one. When asked in the feedback forms to identify what they enjoyed most about the day, the majority of Pride Day participants mentioned the workshops. The session on changes to family benefits legislation was cited most frequently.

Members of the committee decided not to issue a press release, nor to allow the media to enter the premises if they appeared inadvertently. We wished to make the day a safe space for all psychiatric survivors, many of whom feel uncomfortable under scrutiny. One can easily understand this decision. We are typically cause for notice only when we kill someone or when we escape from a hospital. We rarely see headlines such as, "*Mental Patient Obtains Ph.D.*" or "*Psychotic Patient Writes Best Seller.*"

### E. Feedback

We developed a form to elicit feedback from Pride Day participants. The major complaints centred around the limited amount of food. This illustrates how important necessities such as food are to people who live very marginally—a big attraction of our day was an opportunity to be fed. We had anticipated somewhere between seventy-

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<sup>13</sup> Until 31 December 1997, social assistance for people with disabilities in Ontario was governed by the *Family Benefits Act*, R.S.O. 1990, c. F.2. Anticipated changes to the definition of disability under the new legislation, the *Disability Support Program Act, 1997*, being Schedule B to the *Social Assistance Reform Act, 1997*, S.O. 1997, c. 25, resulted in fears that many psychiatric survivors would no longer qualify as "disabled."

five to one hundred people, but close to two hundred attended and we were unable to feed everyone.

Surprisingly, however, when asked to rate the importance of each of the activities Pride Day provided, only a few participants rated receiving food or clothing as the most important part of the event. Perhaps participants who were the most marginalized by society did not have the ability to share their views on paper. Sometimes, psychiatric survivors have problems with literacy, but in other cases people may be simply ashamed of their social status and do not want to admit, even anonymously, that food and clothing are their primary reasons for attending an event. This is especially true for survivors who, while now living in poverty, grew up middle or upper-middle class.

## V. CONCLUSION

Overall, Pride Day was a huge success. The attendance was high and spirit was strong. Despite the reputation of psychiatric survivors as violent, there was not one altercation. People were able to socialize without fear of condemnation or interference. Participants congregated outside the Parkdale Public Library after it closed. Pride Day has frequently been a time to meet old friends from the hospital or group therapy sessions of long ago. Because psychiatric institutions generally do not allow former patients to visit their friends still on the ward, we often lose contact with those who share our most desperate times. Pride Day was an opportunity to reconnect.

Organizing Pride Day is different from other efforts at community organizing in the psychiatric survivor community. It is unfunded by traditional agencies such as the Ministry of Health and is completely driven by members of the psychiatric survivor/consumer community. We wish to attract the most vulnerable members in our community, rather than those who are already activists. Nevertheless, Pride Day draws an audience larger than any other public gathering in our community.

I am conscious of the so-called "objective voice" often used in academic work. For far too long, psychiatric survivors have been quantified and analyzed in a literature divorced from our lives. I did not wish to reproduce the artificial separation between writer and subject by describing our group without input from the membership.

Some members did not want our difficulties to be publicly discussed and published in a public forum. Writing openly of internal disagreement, they stated, could be used by psychiatrists to discredit our

work and the strength and unity of our movement. Others thought it was crucial that we describe ourselves in detail in order to emphasize that we are not more homogenous than any other oppressed group. Others still thought that the article should be more content focused and less process oriented.

Writing this article reflects the very dilemma I face daily in my work. I wish to sensitize lawyers to the struggles of psychiatric survivors and I therefore use legal contexts and exercises to illustrate our experiences of oppression. However, legalese is precisely what distances lawyers from their psychiatric survivor clients.

Despite the inherent contradictions involved in producing this article, I am hopeful that it will contribute to the betterment of my clients. Describing Pride Day in an international journal publicizes and politicizes our encounters with both the psychiatric and legal systems. It also offers psychiatric survivor lawyers the opportunity to join hands with their sisters and brothers who may not share their privileges. As many marginalized peoples have stated over the years in reference to their own political struggles, the liberation of psychiatric survivors must be the work of psychiatric survivors ourselves.