

PEOPLE ADVOCATING for CHANGE through EMPOWERMENT Inc.

329 Waverley Street, Thunder Bay, Ontario



SURVIVING IN THUNDER BAY:

AN EXAMINATION OF

MENTAL HEALTH ISSUES

– Phase Three –

Final Report of the Action Research Team
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Laurie Albertini
Katherine Laurence
Pat Morris
Colin Stewart

Karen Charles – Research Coordinator
Debra Clark - Facilitator
Joy Harasymchuk – Facilitator

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INTRODUCTION

Consumer/survivors comprising the steering committee of the local chapter of the Ontario Psychiatric Survivors' Alliance (OPSA) questioned the lack of a formal consumer evaluation of the mental health system in Thunder Bay as early as 1992. As a result, an Action Research Team was formed to investigate mental health and related issues from a consumer/survivor perspective. The resulting project, *Surviving in Thunder Bay: An examination of mental health issues*, was conducted in two phases. Phase I involved intensive individual consumer/survivor interviews intended to document consistent issues and trends which would form the basis of a concentrated investigation through focus groups during Phase II (PACE 1993 & 1996). Results formed the basis for the direction of services for the newly organized, consumer/survivor directed, People Advocating for Change through Empowerment Inc. (PACE) as it evolved from its OPSA roots.

The past five years since the completion of the original focus groups have been marked by major mental health reform across Ontario. At the same time, consumer/survivors are increasingly demanding a voice in their care and attention to their experiences. In this context, the Action Research Team at PACE was reassembled. The team developed a research agenda designed to elicit the experiences of consumer/survivors in the current atmosphere of mental health care reform and to provide a forum for the generation of recommendations and assessment of change.

The utility of the information generated by consumer/survivor focus groups is well documented by the earlier *Surviving in Thunder Bay* study. The method is particularly well suited to current efforts on the part of mental health system consumer/survivors to direct reform (Ochocka, Griffin & Lord 1998). It is anticipated that the results will provide continued direction for People Advocating for Change through Empowerment Inc, the host stakeholder, and other progressive mental health and social service providers in the region.

METHODOLOGY

Procedure

The current project, Phase III, consisted of a series of focus groups organized around general and specific domains identified as problem areas by consumer/survivors in Surviving in Thunder Bay Phase I and II. Eleven two-hour groups were scheduled over the period from April to September, 2001. Group topics were: 1) Housing issues; 2) Financial issues; 3) Crisis services; 4) Public awareness and barriers; 5) Hospital services; 6) Mutual assistance and self-help; 7) Community resources; 8) Social recreation and; 9) Quality of life.

The development of the questions, organization of the groups, and analysis followed the systematic protocol guidelines set out by Morgan (1997) and others (Krueger 1998, Greenbaum 1998). Key questions, developed and validated through the earlier studies, provided the bulk of queries designed to elicit information on current problems. Additional queries and prompts were developed to build the solution focused aspect of the study in eliciting information about maintenance factors, experiences of solutions, and recommendations. A question regarding recent changes was also raised for each domain to prompt participants to evaluate the current direction of the issue. Moderators were instructed to consider the questions as guidelines, to probe vague, cryptic, or inconsistent comments, and to query for solutions. Recording was via audio tape with back-up notes, commentary, and preliminary coding by the co-facilitator and/or research coordinator. Discussion around each key question or recommendation was summarized by the facilitator.

Analysis was transcript based, organized around the identification of themes, and utilized an ethnographic program, Nudist4, to assist in analysis. Statements of degree were based on frequency, extensiveness, and intensity of expression. Where necessary, a criterion level of agreement was set at 75%. Speaker identities were recorded and collated across groups allowing comments from other groups to be assigned to appropriate themes without single person repetitions.

Facilitator Training

Two experienced group moderators were provided with four hours of training specific to focus group co-facilitation in two sessions prior to the first group. Training followed the guidelines presented by Krueger (1998). A required reading list was also provided. Debriefing was encouraged following each group.

Participants

Posters advertising the dates, times and topics along with cover letters specific to the organization or agency were delivered to agencies in Thunder Bay. Local media were approached and the groups were advertised as community service notes and bulletins in local newspapers and on the community interest television channel. After group three, a

reminder listing the topics and dates of remaining focus groups was sent to all members of PACE with an address on file and to agencies previously notified.

For the eleven groups, the total of ninety participants was comprised of forty-seven different individuals. Groups were remarkable in their changing composition. It appears that most participants were selective in attending the groups by topic and came to the group prepared to speak to the issue. Figure 1 provides a summary of group attendance.

Figure 1: Summary of Group Attendance

Group Topic	Number of Groups	Number of Participants
Housing Issues	2	11
Financial Issues	1	8
Crisis Services	2	12
Public Awareness and barriers	1	10
Hospital Services	1	7
Mutual Assistance and Self Help	1	8
Community resources	1	8
Social Recreation	1	10
Quality of Life	1	16

HOUSING ISSUES

There were two housing groups comprised of eleven participants in total. All participants expressed satisfaction with their current housing situation. Seven identified their current housing as private market rental units. Three identified some type of supported apartment dwelling (Habitat and Alpha Court), and one owned a house. The group identified the criteria for adequate housing as affordable, safe, clean, quiet, and close to transportation, a grocery store, laundry facilities, and medical and social supports.

Poverty, prejudice, stage or severity of illness, and location were identified as factors determining consumer/survivors choices in housing. Participants related stories demonstrating the particular vulnerability of consumers to mistreatment by potential landlords who are aware of the limited options often faced by those with a disability, poverty, or the stigma of mental illness.

I've had to move so many times that now I just pack it up and go...don't even argue...just go to the next place and hope for the best...

Although it was acknowledged that private market rates often forced consumer/survivors to either live in substandard units or spend out of other basic needs budgets, there was a general resistance to apply for government subsidized housing. Many expressed concerns related to a loss of independence with both supported and subsidized housing.

When you take a subsidized housing, the government controls you, where you live, how you live, who can stay over. If you're single you get one bedroom even with grandkids.

Two participants had been homeless as a direct result of the onset of their illness. Across the groups, the threat of homelessness emerged as a frequent and well founded fear among those living with a psychiatric illness.

Well, there was a mortgage and they cut off my pension...just before Christmas they took it (the house) back...left me, basically, on the street.

Yeah, for out of town people after the hospital, there's no place for them. Sometimes they don't want to go back to their community, the treatment is here in Thunder Bay...

In times of housing crisis, participants had utilized Community Residence, Shelterhouse, and Salvation Army Men's Residence, and also had experience with the Lakehead Psychiatric Hospital (LPH) Approved Home Program. Experiences with psychiatric group homes were negative and associated with stereotyping, prejudice, control and verbal/emotional abuse. The integrated crisis housing services were more favorably discussed. However, these were also seen as overly controlling, lacking in adequate staffing, and marginal in terms of services and assistance to the mentally ill.

After my breakdown, I had no place to stay. I was too well to go back to the hospital, but obviously not well enough for anybody to give me a house or an apartment at that point...so they put me in what they called a Home for Special Care...very nice meals, very nice home, nice neighbourhood...but they treated me like a juvenile delinquent...those months at that home were actually worse than the time I spent at the hospital.

The (LPH) Approved Group Homes are very patronizing...extremely, almost, more as if they thought we were developmentally delayed...because the mental illness was stamped on me, I was all of a sudden 10 years old again. One time I bought a really cute hat. I don't normally buy hats but I thought this was a cute hat. She took it off my head before I went outside because she said if you stand in front of my house wearing that hat people will know that mental patients live here...

Because they have a difficult time getting people to care for individuals with a mental illness, they will take anybody...

Consumer/survivors saw significant positive changes over the past five years in the area of housing and felt that this was due to increased availability of private market units and the resulting competition. Landlords appear to be less inclined to ask tenants to sign leases and are less stringent about second month's rent, both of which tended to present particular problems for group members in the past. The chance of losing one's apartment due to hospitalization or becoming homeless as a result of relapse had lessened with shorter term hospital stays and an increased awareness of the problem on the part of financial assistance providers.

In terms of solutions, the group suggested that having a case manager (social worker, case worker) could relieve many of the housing problems encountered by consumer/survivors, by providing assistance, information, referral and advocacy for the client and reassurance for the landlord.

Additional solutions offered by the group included the following:

- in acknowledgment of the association between untreated mental illness and homelessness, efforts should be made to provide non-threatening, non-coercive and easy access to medical care and appropriate supports to inhabitants of crisis housing
- housing advocacy and practical assistance in finding and viewing potential apartments should be mandated to one or more of the community based agencies involved with consumer/survivors and be readily accessible without a referral
- encouragement of consumer/survivor participation at the tenant association, workplace, and board levels of not for profit housing agency
- people coming in from under serviced areas require housing and culturally relevant supports

FINANCIAL ISSUES

Eight participants attended the financial issues group. The group discussed barriers to acquiring and maintaining employment including blanks on resumes, inflexibility in the workplace in coping with the cyclic nature of some mental illnesses, and the barriers created by poverty (telephone access, transportation, clothing and training) and misconception. Participants also identified barriers inherent in social assistance programs. Fear of losing drug coverage and concern over reapplying were primary barriers to working for consumer/survivors currently on assistance.

Employment and work experience offered by agencies was generally viewed as ineffective and demoralizing. Consumer/survivors were expected to take jobs that were underpaid or unpaid. Many were advised of where to set their expectations based on preconceptions and stereotyping.

I'm trying to re-enter the work force after being lost for a year and a half. So, my worker was helping me with my resume and my covering letter. And I actually got an interview. I called her up after the interview and told her I didn't take it because they wanted me to do all these things plus volunteer for \$7.50 an hour. She thought I had a really negative attitude and said I should be happy to get a job....

Everybody has a maximum potential and just because someone has a mental illness, you don't put everybody in the same basket. It doesn't matter how sick an individual is, they have a certain level that they can reach if people help. To lump everybody into the same book, the same label, the same restrictions, the same control, you know, they're making people sicker...

While the vocational rehabilitation program was viewed negatively, adult education programs, and the local college and university were positively regarded by consumer/survivors across groups. Acquiring funding, illness and relapse, medication effects and fear of failure were perceived as barriers to education.

The people at Lakehead were great and did lots to help me but you've got to get some funding first...that is almost impossible...we talk about changing things in work and school so to accommodate the illness but what's the use if you can't get a foot in there...

I applied at the university. I was really embarrassed but I knew if I was going to go to school that I would have to get some funding. I went and they handled my illness well. They got me money to go. And in the end when I was too sick to go, they said, "we'll look at this as a detour"... Yeah, they were good to me...

Issues related to acquiring and maintaining financial assistance were also discussed. The forms and the process for application were viewed as intrusive, degrading, and difficult to

complete, particularly if ill or confused from medication. It was also felt that, in terms of application, the role of the family doctor as sole gatekeeper was inappropriate. Group members reported major differences in treatment by workers, which was often reflected in how much information was provided to them about additional benefits. In general, social assistance was perceived as more secure relative to employment.

Seven of the eight participants identified poverty as a daily reality in their lives and all admitted to living with the fear of losing assistance. Consumer/survivors identified both obvious and insidious effects of poverty including: isolation; marginalization, stigmatization and resulting abuses; safety and security issues like telephones and emergency child care; disempowerment through contact with agencies operating under “archaic power and control philosophies”; and criminalization of activities intended to make extra money, such as sewing.

I don't have a phone. I walk when I need help to a phone booth and I make my call to Crisis Response. That's usually early, early morning, like 1 or 2 in the morning...

Consumer/survivors from all groups relied on food banks, soup kitchens, consumer organizations like PACE, and other free services to survive. Church organizations were recognized but, with the exception of the Salvation Army, rarely accessed.

In terms of change, the group noted little positive improvement in the area of employability with the exception of the rapid reinstatement policy for those receiving disability. Many saw the depersonalization of social services through automation as a sign of the increasing gap between providers and consumers. Cutbacks, understaffing, and the policies of the current government were seen as leading to a further erosion of respect and an increased big brother attitude. Financially, all participants felt more impoverished and less secure than in the past.

Many felt that the recent involvement of consumer/survivors as representatives and the success of consumer/survivor driven organizations like PACE have changed expectations and created an awareness of the discriminatory social policy and unfair limitations.

Across groups, participants felt that there is a role for PACE in the facilitation of consumer/survivor business and skills development. Some participants felt that the computing field was well suited to accommodating illness effects, such as sleep disruption, and there was frequent reference to website development as a training and business venture. Others discussed a skills bank or team effort type of business. In both cases, participants saw these enterprises as being under the “management” of PACE.

Additional recommendations were as follows:

- consumer/survivors need to be educated about their right to be treated fairly and should not accept the pretense that the mental health consumer's work is less valuable
- PACE should obtain copies of social assistance programs' policy books for consumer/survivors to reference

- true case management/advocacy should be available for every consumer/survivor
- “real education, real wages and real jobs”
- the mental health system needs to set a precedent by hiring consumer/survivors and to be at forefront of devising a flexible organizational system to accommodate the abilities and disabilities of all its employees
- stereotyping and discrimination should be addressed by consumer/survivors through public speaking and education, consumer/survivor run agencies such as PACE, consumer/survivor representation on councils and boards of directors, and by prominent consumer/survivors “coming out”

I remember hearing a story one time about the CNIB. The big wig was talking at a press thing about the blind being stigmatized and stuff and a reporter asked him how many blind people the CNIB employed...this was some time ago and the answer was none...

Yeah, something so obvious...it would be nice to see that little note at the bottom of all ads for mental health workers...you know like “The Thunder Bay Regional Hospital encourages applications from women, minorities and those who have experienced mental health problems” ...

We have to get qualifications that are recognized first...there’s lots standing in the way of that and to keep the job they have to make changes in the job...it causes a lot of resentment and stress can be so bad for someone who is struggling with any illness...

Yeah, work’s a tough one...you don’t want to fail cause they use that against us all...its lots of pressure...and its like they make it as hard as they can...

CRISIS SERVICES

Twelve consumer/survivors participated in crisis services discussions. The group was notable for the amount of information exchanged among participants. Positive and negative aspects of various crisis services in Thunder Bay were discussed. However, it was remarkable that the majority of participants chose to go for help to agencies not mandated to provide mental health crisis services. The Northern Women's Centre, PACE, Beendigan, family doctors and Shelterhouse were frequently accessed and were perceived as more caring, less controlling, and more accessible than mandated crisis services. Traditional hospital services were contacted as 1) last resorts 2) when the consumer required psychiatric intervention to access medication or 3) to "withdraw from the world". Some of the crisis services offered by mental health agencies were viewed as "not really a crisis service" Others noted that there are so many programs, each having their own restrictions, that many not only "slip through the cracks", but it also becomes too easy to pass the buck.

In the course of experiencing a mental health crisis, consumers also came into contact with police, ambulance attendants, family and children's service agencies, detox and other peripheral groups. The problem of stigma and discrimination was again discussed in this context, particularly with regard to treatment by some police and ambulance attendants, and social workers.

I've found my neighborhood police officer to be helpful and I avoided a lot of stress last time it got bad by going to him and he got me down to the hospital. It had happened before where I was put on the ground and cuffed mostly because I was scared...

The Children's Aid took my first baby when I first got real sick and then when I had the second one they came again but there was no time in between that they offered me anything that could help me...its like cause I had a mental illness I was hopeless...I know a lot of people who needed care for their kids when they had to go to a hospital for other illnesses and they never saw Children's Aid again.

Participants saw the development of mobile crisis response as the single most important change in mental health services in the past five years. Most recognized problems but acknowledged that these programs are in their infancy.

When I got here, I was so sick...I was looking for the LPH and I stopped by the side of the road and just broke down...I guess hysterical...the people at the daycare centre called the police...I would like to see the day come that people pick up the phone and call crisis response instead of the cops when someone is sick like that...

In terms of solutions, the group presented recommendations designed to increase the accessibility and efficiency of crisis services and reduce mistreatment. Many participants

addressed issues that contribute to crisis, such as poverty and stigma. Others identified methods that may help to avert them, such as reducing isolation, increased peer support options, and good case management. Weekends and holidays were identified as particularly crisis prone. It was recommended that services, including PACE, need to be at full complement during these times.

There is a lot of inflexibility out there...in schooling and work and treatment and finance...and you've even got to fit your needs into the normal work week...

Some of the group's additional recommendations are summarized below.

- 24/7 crisis response
- there is a need to coordinate or amalgamate agencies / provide knowledgeable case management to all consumer/survivors or provide a viable referral service so that an appropriate crisis service is available to all consumer/survivors
- a panel of consumer/survivor consultants be established to provide training to organizations, (professional and non-professional) to deal with the issue of public fear and stereotyping
- continue efforts to replace reliance on the police in crisis intervention
- devise a buddy system similar to sponsorship where those having knowledge of system may be able to help those with less experience learn the system

PUBLIC AWARENESS AND STIGMA BARRIERS

The stigma associated with being a consumer/survivor was acknowledged by the group as being highly pervasive. Its effects were apparent in relationships with family, friends, and partners. It was also apparent in interactions with government services, schools, police, medical staff, landlords, employers and even other consumers. Stigmatization and the fear of being stigmatized were identified as factors influencing crisis, isolation, lack of motivation, treatment non-compliance, and poor self-esteem. Stigma effects were felt by participants as abuse, disrespect, and differential treatment. Participants cited personal experiences ranging from blatant abuse in institutions, to being shamed by family doctors who did not “believe in” the diagnosis, to being lectured for refusing to work for less than minimum wage. Consumer/survivors frequently complained of being dismissed, ignored, and treated as if they were children incapable of making decisions. Others were assumed to be learning disabled, dangerous to children, malingering, and even hearing impaired. Furthermore, participants felt that stigma was based solely on the fact that they had a diagnosis. That is, no indication of illness needed to be apparent. As one member stated, “Our Star of David is our diagnosis”.

Sitting in a lecture one time the professor was talking about behavior modification, and made a comment like, “ If your client has a psychosis don’t even bother to refer them cause it can’t help them ”. I wanted to correct him really bad...to say that he was giving everyone there the impression that people who have schizophrenia don’t experience all the normal problems other people have, like grief and phobias and can’t be helped in these things because they have a serious illness...I was afraid everyone would guess if I spoke out that I was one of them...

Group members referred to similarities with gender and racial prejudices in suggesting reasons why people stigmatize the mentally ill. It was suggested that stereotyping and sensationalization by the media, marginalization by the government, disempowerment, and poverty are primary contributors to the problem.

Interesting that the government has the power to take the stigma away and to create stigma... The joke is when I was a kid, you’d go into the pharmacy and you say, “I’ll have a pack of Marlboroughs, <whispering>and some condoms”. Now you walk into the drug store and you say, “Let me have a pack of Sheiks! <whispering> and some Marlboroughs”...

Increasing poverty or fear of impoverishment, a repetitive issue in all the groups thus far, was cited as having the single greatest impact on the degree to which consumer/survivors are mistreated. As one participant noted, “If you have money and a mental illness you’re called eccentric. If you’re poor, they call you nuts”.

The group felt that there had been slight improvements over the past five years and attributed most of these to changing attitudes and empowerment among consumer/survivors themselves.

Well, there is more organizations like this, that are totally driven by consumer/survivors, as well as ones that are run half and half, like the Patients Council, or CMHA (Canadian Mental Health Association), and I think that's helpful. I think when people finally take power into their own hands, they learn what they can do.

Although concealment of the mental illness, where possible, was a common mechanism for avoiding stigmatization across all groups, many consumers felt that silence only contributed to the problem of stigma. Many had successfully altered the opinions of others by selectively timing disclosure and saw “coming out” and making contact as an important to eradicating stigma.

I think sometimes what you do is almost like a strategy, you don't necessarily lie, but you don't disclose that you are mentally ill until the person knows you as a person...

The group was strongly solution focused and presented a number of recommendations:

- that a panel of consumer/survivor consultants be given a mandate to work within the human service network to educate and advise and that this training be made a part of the curricula for all human service occupations
- that problem organizations acquire an ombudsperson who is a consumer/survivor
- there should be meaningful systematic evaluation by consumer/survivors of the quality of care provided in the mental health sector and a secure independent forum to review complaints
- that advocates be made available in the community
- that the government take affirmative action and demonstrate their confidence in the abilities of all people by hiring mental health consumers
- that the government acknowledge the problem and utilize the resources at their disposal to defeat stereotyping
- that the dual burden of stigma and poverty be addressed
- prominent consumer/survivors need to ‘come out’
- agencies should encourage consumer/survivor attendance and participation at all “workshops that are about us”
- consumer/survivors need to come together more, whether to seek more involvement in their care as in the patient council or the Canadian Mental Health Association (CMHA), or to seek more involvement in the community as in PACE

Speaking out every day and in every part of life to make sure everyone is treated equal...

Remember the stigma that used to be associated with cancer...it's gone away...we need to study how did they get rid of that? What kind of campaign managed to get rid of it...

Powerful people need to acknowledge it (stigma) before anything can be done about it...

Let people see a face...someone who has the strength and the courage to answer questions honestly and openly...

HOSPITAL SERVICES

The group was attended by seven consumer/survivors. All had experience as psychiatric inpatients at one or more local hospitals. Many also had experienced inpatient care at other Canadian hospitals. The group was noted to be particularly cohesive.

In general, participants were primarily admitted to the hospital by family doctors or emergency on call doctors at the regional hospitals. The need for medication, acute illness, and withdrawal from stressors were the most frequent reasons to seek admission. Access to outpatient programs, acquiring a case worker, referral to appropriate services, housing assistance, and accessing a psychiatrist or family doctor were also benefits gained through hospital admissions. The advantage of involvement with an outpatient program was also evident when attempting to gain re-admission due to relapse.

Consumer/survivors identified a number of issues related to “power and control” in discussing their past and recent hospitalization for psychiatric complaints. The group repeatedly returned to the issue of the stigmatization of mental illness and its resulting prejudice. Members of the group provided the following descriptors of the inpatient “system”: dominating; controlling; abusive; demoralizing; disempowering; humiliating; crushing; consuming; and punishing. Although the group identified systematic prejudices and abuses in all medical facilities, general hospitals were perceived as a less restrictive, more respectful, and safer environment. General hospital staff were also identified as being more “modern” or “psychosocial” in their approach.

In the mental health system, especially in hospitals, the person who's respectful is the one who's rare and unusual...

Most participants viewed the imminent closure of the LPH favorably. They perceived the problems of stigma and prejudice as being ingrained to the extent that the environment was “contaminated beyond repair”. The condition of the building, except for the outpatient area, was deteriorating, and staff were viewed as “caretakers rather than caregivers”. Concerns around becoming “institutionalized” or dependent were also noted. Many felt that this was an opportunity to end the old ways of dealing with mental illness, by segregation and shutting away. Participants felt that the resulting integration of care for all illnesses in one hospital, and the placing of caregivers in the community would be more beneficial to consumers in general.

I know when I first went to the LPH, I used to get off at the Port Arthur Hospital and walk ... then go in behind and up around the back because I didn't want anybody on the bus to know where I was going. Then, finally, it got too cold...that was a real struggle, that went on for months.

I lived in Ottawa and one of the best things was that the psychiatrists are out there in the community...

There was, however, a great deal of concern over the potential loss of many of the LPH outpatient services. The concurrent disorders program, patient council, and the patient

advocate, were all highly regarded by the group. Consumer/survivors expressed skepticism about promises that services would be transferred to the community. The convenience of having a treatment team located in one place was noted, although many struggled with the stigma attached to the site. In general, loss of contact with outpatient service providers was generally perceived as a greater threat to care than the loss of inpatient beds.

The group felt that the treatment of consumer/survivors hospitalized for medical problems or reporting to emergency with medical complaints depended on whether one's psychiatric diagnosis was known. Many had experienced being ignored by medical staff or dismissed as malingerers.

You lose all credibility when you are labeled with a mental illness no matter how you behave...

I was having blackouts. I could not convince them that the blackouts felt like the ones I remember as a child with epilepsy...of course that's what it turned out to be...

Medication arose as a frequent topic across groups. Although consumer/survivors repeatedly identified medication as the most effective treatment for many illnesses, they frequently complained about side effects, lack of progress, and the proliferation of psychiatric drugs. Side effects such as marked weight gain, lethargy, sleep disturbances, nausea, coordination and concentration problems were the most frequent reasons cited for medication non-compliance. Changes in medication frequently accompanied changes in physicians and many were concerned about the lack of opportunity to participate in their own care. Stories relating over or under medicating were common. Persistent fear of losing coverage for necessary medications and concerns over accessing physicians were also considered primary barriers to quality of life.

So, you're all excited and you're going to do something, and then the medication kicks in, so, I'm sleeping for the next four days...they should try some of their own stuff...

Medication is so important...I needed my prescriptions renewed. I went to a doctor who, in this town who knew me when I was a kid. The answer I got was, "that medication you're on is for crazy people." That's exactly what I was told. He gave me something different which didn't even have any effect...when I went back sicker, he avoided me...wouldn't even see me...

Everybody wants you on their medication...I've got seven diagnoses...one for every doc I have seen...they just won't listen to you and believe me, I am an expert...

Consumer/survivors acknowledged many changes over the past five years. Most of these were related to the move to integrate the care of mental illness into the community and provide alternative supports which have substantially reduced the average hospital stay. Similarly, participants saw changes that they attributed to increased respect of patient rights. They attributed these latter changes to 1) consumer/survivor awareness about their rights as patients 2) increased opportunity for consumer/survivors to come together to “*tell their stories and learn that these things were happening to all of us*”.

Consumer/survivors offered a few solutions to medication issues. The advantages of an open, long-term relationship with a doctor and pharmacist were noted. Self education about medications, persistence with physicians in seeking involvement in one’s own care, and advocacy in gaining coverage for medications were also demonstrated by consumer/survivor stories.

The more articulate you are, the more informed you are about your condition, the better treated you are. So, I was eager to walk into LPH and say exactly what my illness was, I took my pill bottles with me and, and stated simply that I need a repeat, and this is what I normally take and all I need from a psychiatrist, is regular blood tests to make sure that my levels are ok...I was quaking in my boots... terrified...But that’s the way that I got help.

Participants suggested that continued consumer/survivor empowerment and concentrated efforts to eradicate prejudice would improve in-hospital care. Patient advocates were also identified as invaluable and the need for advocates in the community was noted by the group. The group identified the patient advocate as a buffer to the fear of being refused care for speaking out about mistreatment.

I haven’t heard a thing or plan on getting patient advocates in this community... we need those in the community...I’m talking about somebody who’s got the education and the power to make things right...

Other recommendations and solutions presented by the group were:

- that providers steer clear of concentrating services specific to mental health in one place to avoid having a stigma attached to a particular area
- that every effort be made to encourage the integration of mind and body health care
- that case management be recognized as an important factor in ensuring both continuity of care and quality of care in the deinstitutionalization of mental illness
- that agencies and hospitals providing care to the mentally ill involve consumer/survivors in policy making decisions and quality of service “watch-dogging”
- PACE and CMHA were considered ideal settings to house patient advocates
- *instead of people being hospitalized, there needs to be a good supportive place to stay when people need to get on or back onto medication, you don’t need to be in a hospital environment*

MUTUAL ASSISTANCE AND SELF HELP

The group was attended by eight consumer/survivors. Experiences with peer supports were common and the group discussed formal and informal peer support networks. All participants were members of formal peer support agencies such as PACE and the CMHA Clubhouse. Most had self-referred to these supports. Many also had experience in professionally facilitated support groups to which they had received a professional referral. Participants perceived these groups as more controlled, more solution oriented, and more like formal treatment. Concerns were related to a sense of distance from the facilitator, who often failed to share the same frame of reference. Mandatory attendance requirements were also a concern.

I can discuss (living on) \$930.00 a month with my peer group, but I wouldn't touch that with the doctor because it's a waste of time. They don't understand that. But that's a big thing, to try to live on \$930.00 a month...

There was little experience among participants around peer support groups organized by diagnosis. However, the majority of the group expressed enthusiasm for diagnosis specific internet chat rooms and mental health advocacy group sites. For some, the preference related to feeling less inhibited by stigma and confidentiality issues. For others, the internet offered contact with an otherwise limited consumer base for rarer or less recognized illnesses.

Most members of the group also had experience with peer support groups unrelated to their particular mental illness. Twelve step programs such as Alcoholics and Narcotics Anonymous, Al-anon, and Alateen were frequently attended. Issues for mental health consumers associated with these groups varied considerably according to the composition of the group. Many chose not to disclose their illness and, as a result, felt as if they could not fully benefit from these honesty-based programs. In general, consumer/survivors felt more comfortable in groups where one or more members also identified a psychiatric diagnosis.

I have friends both outside and at PACE I feel comfortable at PACE because they understand the situation I am in. I see an understanding and acceptance. Whereas, like friends, you know, if I mentioned how I get depressed and I have suicidal thoughts, they look at me in a different way. They think it's self-pity...

Participants cited the following as some of the benefits of peer support groups in general: 1) emotional benefits such as the sharing of information, coping strategies, and resources; 2) a sense of empowerment through association and; 3) friendships, social and recreational involvement, and job opportunities. However, inherent problems were also noted. Confidentiality was cited as an issue by a number of participants. Others had encountered hierarchies in groups of a long-standing nature. In some cases, fear of stigmatization was intensified by “stepping out with” or associating with the group.

I felt empowered...I want to go to school and one of the people in the group there is just finishing university...it's kind of like an incentive for me, you know, it's empowering. I used the programs through the LPH and felt more like a commodity...it is kind of degrading after a while because the people who are there are getting paid. The other group is empowering because they have been through a lot of things, and you know, they can help other people, not for money.

Participants also frequently noted that transportation was a major barrier to increased peer socialization and group involvement. The majority of participants relied on city buses and cited scheduling, cost, location, and safety issues as influential in determining motivation to attend peer support opportunities.

Gaps in peer and group supports were felt to be minimal. However, the isolation of consumer/survivors and complete lack of services, professional and peer support, for those living in northern communities was noted throughout the groups. Two participants felt they could not return to their community because of the lack of care for their illness and additional problems were encountered by group members seeking culturally relevant support.

I started going to a stop smoking program, taking Ti Chi, and a healing lodge... there was encouragement to talk and I mentioned that I was manic-depressive...He said "I don't think native people should be on medication," and then went on and talked and talked and I stopped talking and then stopped going...

Participants felt that changes over the past five years were: 1) increased social activism among consumer/survivor peer support groups; 2) increased access to peer support and specific diagnostic groups through the growth of the internet; and 3) increasing emphasis on getting people connected with peers (ie hiring of a membership director at PACE).

In discussing ways to enhance consumer/survivor access to peer support, participants felt that there is a lack of acknowledgement of the benefits of peer contact to illness recovery and quality of life on the part of funding providers. Most felt that consumer/survivor groups could benefit from advertising and promotional funding.

When I am in a crisis I come here first...many of us do...and sometimes its all I need...

I think it is really important for people who are new to the system to have this kind of contact because the system can eat you alive if you're on your own...just to think of how much I know now and how much difference knowing so much would have made...here you can benefit from a thousand experiences...

The following observations and recommendations were also presented by the group:

- drop-in peer supports were identified as preferable to those requiring an attendance commitment
- facilitated groups could benefit from trained consumer/survivors as leaders
- the focus groups, emphasizing information and solution sharing, should continue as there is a need for consumer/survivors to address current issues and provide input to mental health groups, agencies, and consumers
- consumer/survivor directed facilities such as PACE should encourage/welcome efforts to host twelve step groups thereby encouraging the participation of consumer/survivors in peer directed recovery groups
- the tremendous gap in service for those living with a mental illness in northern isolated communities can be partially addressed through a toll-free peer support telephone line initiative
- the issue of transportation should be addressed, perhaps through co-operative ownership of a vehicle and a hired consumer/survivor driver, such that illness and medication effects are less likely to hinder involvement with peer groups

COMMUNITY RESOURCES

This group of consumer/survivors had experience with numerous community based services. The group primarily discussed professional counseling services, services dedicated to specific problems such as addictions programs, mental health agencies offering professional support, and mental health agencies or programs offering peer support. At the time of the group, most participants were associated with support programs for psychiatric service consumer/survivors through Alpha Court, LPH outpatient services, or CMHA. All eight participants were members of PACE.

While most participants expressed satisfaction with their current involvement, stories frequently demonstrated problems related to accessing resources, particularly for those not coming from an inpatient setting. All of the group members felt that they had entered the system unaware and many remained uninformed in spite of repeated contact with professionals.

Even for those having an awareness of an appropriate program or service, obtaining a referral was often a problem. Many programs and services require referral by a physician and present a particular hardship for those not having a family doctor or timely access to a psychiatrist. Participants also frequently referred to the “run around” which, for access to some services, required “passing muster at all kinds of levels along the way”. Of particular concern was the need to undergo an assessment procedure “everywhere you go for any kind of help whether you’re sick or healthy”. Additional problems related to accessing services included 1) waiting lists for programs perceived as good programs and 2) inflexibility in agency criteria.

In general, while satisfaction with existing services was high, experiences of navigating the system and acquiring the necessary supports for health and living were viewed as extremely stressful, frustrating and illness provoking. It was agreed that the most effective way to access all types of services, including obtaining family physicians, psychiatrists and a case worker, was to be admitted into an inpatient setting. Case workers were particularly valued for information, advocacy, support and referral.

Consumers need to be speak up for themselves but, when you're sick, the community has to come together for you and someone needs to manage that...

Problems related to misconceptions about mental illness were also discussed by the group. Numerous stories reflected inappropriate referrals and errors in treatment as a result of the failure to recognize the consumer/survivor as an expert in their illness. Many experienced condescending attitudes and evidence of prejudice.

You know ...that's the stigma kicking in. They think you don't know anything, you're mentally ill, you're sick and I'm the professional so I know better.

Consumer/survivors noted the following changes in the area of community mental health services in the past five years: 1) The issue of obtaining and keeping a family doctor had surfaced as a major area of concern within the past few years; 2) Specialized treatment programs, such as addictions, were seen as progressing in their treatment of people with a concurrent mental illness; 3) There has been more of an attempt to introduce culturally relevant approaches to mental health 4) The opportunity for consumer/survivor involvement at the policy level has increased in the past few years.

The group produced the following suggestions:

- referral is a problem which can be streamlined by the assignment of a case manager to every consumer/survivor and a decreased reliance on the family doctor, psychiatrist, and hospital
- there needs to be a single standard assessment which is portable
- coordination and continuity of care is a problem which could be alleviated by an independent and knowledgeable case manager working with the client to navigate the system from the beginning
- the long term nature of many mental illnesses needs to be acknowledged by community mental health services and supports/resources need to be accessible in health as well as illness
- employment considerations should be altered to facilitate the employment of consumer/survivors in the provision of community mental health
- attention should be given to the fact that the information and skill accrued by experienced consumer/survivors remains an untapped resource of particular value to those newly diagnosed

SOCIAL RECREATION

The group was attended by ten consumer/survivors. This group was remarkable in terms of the number of instances of information sharing among participants, with 18 noted occurrences of mutual help and referral interactions.

All participants acknowledged a belief that consumer/survivors tend to be more isolated than “regular people”. The group felt that the effects of stigmatization, poverty, and medication accounted for many of the problems consumer/survivor’s encounter in this area. Participants cited examples of how the stigma associated with mental illness resulted in the loss of extended family, friends, cultural contacts and church or club involvement, and employment. In considering the relative merits of integrated versus segregated recreation and socialization, participants commented that the danger of being stigmatized was a primary factor influencing choices.

Medication or illness effects were also particularly problematic in the area of social recreation. Lethargy, weight gain, coordination, and sleep pattern disruptions were cited as being the most inhibiting.

Sometimes, with depression, you just stay home for days. If you have no money, no transportation, the sheer energy required to go out is phenomenal – overwhelming...

I love to laugh, you know, and I do have good days and then I have slumpy days for one week, two weeks. Last week I just stayed in my pyjamas. The thing is a constipation, you know, like if you don’t have the transportation then you say, “what the heck, I’m going to stay in my pyjamas”, and you just get lower and lower...

Even some place where you could phone someone and say, listen, I’m feeling this way, you know, and they’ll come pick you up send you a taxi and you could come over here...

Financially, transportation emerged as a significant issue, particularly in the winter months. Walking and bicycling were the primary modes of transportation. Buses were used as a necessary but undesirable option for long distances, or as weather, illness or disability dictated. Slightly over half of the attendees regularly purchased a monthly bus pass and considered it essential. In general, across groups, the Thunder Bay Transit services were poorly regarded due to scheduling.

In general, participants primarily attended free activities, libraries, and recreational opportunities offered by PACE, CMHA, and the LPH. Finances precluded perceived ‘normal’ activities and past-times such as cable television, attending concerts, or having coffee or a meal out of the home. Intermittent involvement in volunteering was common, particularly in regard to mental health activism, and was regarded by the group as a positive experience. Friendship with other consumer/survivors was frequently

acknowledged as an important and routine source of socialization. Peer support groups related to specific illnesses, Alcoholics Anonymous dances, and accessible internet chatting through the public library, university or PACE were also cited as sources of social networking. The majority of participants indicated that they preferred the company of other consumer/survivors.

Physical activity was acknowledged by the group as an important aspect of wellness. Most of the participants acknowledged frequent walking, bicycling or fitness routines. While two participants possessed gym memberships and four others expressed a desire to independently join a gym, the cost of such activity was viewed by the group as prohibitive.

The group acknowledged the efforts of CMHA, PACE and the LPH to provide recreational and social opportunities to consumer/survivors, although limited hours of operation were a major concern. The activities provided by CMHA and the LPH were perceived as being highly structured, somewhat controlling, and less desirable. Activities at PACE were perceived as allowing greater flexibility and independence. Some members of the group were discomforted by the potential stigma of being identified as part of LPH and CMHA groups on outings due to the obvious supervision by workers. In general, it was felt that there is a lack of support and opportunity for integration for consumer/survivors.

In terms of change over the past five years, participants felt that increasing financial constraints are particularly noticeable in declining free recreational activities. For the majority of participants, most of whom rely on social assistance programs, social and recreational budgets were non-existent. The failure of subsidized income programs to keep pace with the standard of living and an increasing attitude among service providers that recreation is a luxury were recognized as problems in negotiating solutions. Concerns over the potential loss of recreational programming by LPH upon closure were also noted.

There's a belief that social recreation is a luxury that we don't deserve or need. We don't need luxuries because we don't work hard enough...we don't pull hard enough on our boot straps...

In addition to confronting the issue of poverty and stigmatization, the group offered the following solutions to problems encountered in accessing recreation:

- consideration of extended hours of operation, particularly encompassing weekends, for agencies such as PACE
- increased opportunity for integrated recreation by developing agency associations with 'non-psychiatric' groups such as 55+ Centre, Lakehead University, City of Thunder Bay community and recreational programs
- increased facilitation of individualized social recreational opportunities in addition to traditional organized groupings
- efforts on behalf of PACE and CMHA to assume the recreational functions provided by the LPH

- increased effort to encourage and facilitate placement of consumer/survivor volunteers
- lobbying to secure recognition of socialization, recreation and fitness as a necessary part of healthy living in the calculation of basic needs allowances
- *PACE could look at a professional volunteer manager who could come in to help us to set up a program so that volunteers are recruited, stay longer, and are less likely to burn out*
- *PACE social recreation committee should revisit the membership survey of four years ago to evaluate their direction*

QUALITY OF LIFE

Sixteen participants attended the Quality of Life focus group. The group was notable for the number of first time attendees.

Participants discussed changes in the quality of their lives as a result of their illness. For many, formal diagnosis and treatment came only after years of untreated illness, misinterpretation of symptoms, and attempts to cope using alcohol and drugs. In these cases, quality of life was perceived as improving with diagnosis. For others, the onset of illness was more acute and was associated with a loss of quality of life as the result of a lowered standard of living and stigmatization. Four members of the group indicated that they had lost their jobs as a result of their illness and three others discontinued post secondary educations.

A lot of people, when they get sick, they lose a lot of things. Your lifestyle changes dramatically, the people you know change, everything changes, you know...

And there is no recognition of that either...of having to cope with knowing you have this illness and also dealing with all that loss at the same time...

The group considered a number of factors as contributing to the general quality of life of consumer/survivors. These included good medical care, social support, positive regard by others, and a sense of security with regard to financial support, housing, access to medications, and self-determination. Intrinsically, empowerment was viewed as a critical component in determining quality of life in terms of maintaining independence and securing needs. However, the formal mental health system was perceived as generally disempowering. Many related personal stories in terms of a struggle to “avoid being consumed by the system”.

The majority of group members were struggling financially. Even those with relatively stable employment acknowledged that the fear of even greater financial stress competed with the reality of stigmatization and current levels of poverty as a major barrier to peace of mind, health, and quality of life. Participants also discussed other fears as consumer/survivors and identified the following as threats to the quality of their lives: judgment and rejection by others; withdrawal of treatment; loss of financial support; inability to afford medication; loss of housing; and loss of control. Suicide was not reported as a fear but as an option for regaining control.

Over half of all attendees at the Quality of Life group indicated that they had entered the mental health system with the additional problems associated with alcoholism/drug addiction. Many identified the use of alcohol/drugs as a coping mechanism to deal with a poorly controlled or undiagnosed/untreated illness. The recent recognition of concurrent disorders was viewed by the group as a positive change.

The group discussed empowerment as a solution to many of the internalized limiters of quality of life and wellness, and as a tool in securing basic rights and needs. Indeed, the theme of empowerment was strong throughout the groups. Consumer/survivors defined empowerment in terms of self-efficacy /self-esteem. A number of external and intrinsic factors were viewed as responsible for the common disempowerment of consumer/survivors. Most frequently, group members related disempowerment to poverty, stigmatization, hospitalization, and methods of treatment and program delivery by mental health service providers and social assistance programs based on stereotyping and marginalizing.

I guess they didn't know if I was sick or not because I was so angry and out of control, so I guess they kind of abused me in a way where they took all my clothes, you know. You were in there stark naked and then they jump on you and then they throw an injection into you. A little while later you're out cold, you know. But I think, I think I was abused there. All control over your own life is gone.

Consumer/survivors identified a number of situations which were perceived as contributing to regaining a sense of empowerment. A frequently recurring topic included coming together with other consumer/survivors. Stories describing empowering experiences as a result of involvement with other consumer/survivors were commonly related to:

- the strength/power of numbers
- an awareness of and opportunity to participate in consumer/survivor activism
- an awareness of rights
- an opportunity to talk about experiences and illness without stigma effects
- gaining and sharing knowledge about the illness and treatment
- learning and sharing survival skills
- seeing other consumer/survivors “make it” or showing others that it is possible
- a safe place to express righteous anger
- a sense of community / belonging
- opportunities for employment, volunteering, recreation, friendships, and helping others

Get a bunch of us around the table the drug conversation would scare psychiatrists. That's internal education and it can save your life. Then there is also the external social education, where we do the thing of releasing the stigma, which is what we try to do as a group like CMHA or PACE...

PARTICIPANT EVALUATION

I've been around a long time and I know I participated in lots of research which I think was just about someone getting their degree...That's not right and there was no benefit to me...when I go home from here I feel better in my illness and I feel like I am accomplishing something that might help just one other person...in the group...or through someone who learns something because of the official report...

Fifteen participants who attended two or more groups and randomly chosen groups were asked to reflect on the group process in terms of arriving at solutions, to consider whether the group met their goals and expectations, or/and were asked to comment on the moderation, format, and group environment. Altogether, fifty-two comments attributable to 38 participants were recorded. All but three participants expressed satisfaction with the groups. Many participants expressed faith in the focus group process but had doubts about the implementation of suggested strategies. Some, familiar as participants in quantitative studies, perceived focus groups as a more consumer directed form of research. Compliments to the moderators were frequent and participants also frequently recommended continuation of the focus groups after completion of the study. Group four and seven were randomly chosen to receive a somewhat standardized formal anonymous evaluation. The return rate for the pre-stamped, addressed questionnaire was extremely poor (<20%) and all comments were favorable.

There is a lot of fear out there based on misconceptions and yeah, they want to keep the status quo. Stuff like this, being in these groups that aren't about talking about your own problems, but are to try to change things out there. That would have scared a lot of people a few years ago....

Or made them laugh...

Yeah, but now its taken more serious because we all together know they're not right and there's power in numbers

SUMMARY

The combined issues of poverty and stigma were dominant topics in all groups and are seen as having drastic effects in every facet of life including contributing to and maintaining the illness. Participants related experiences demonstrating a systematic prejudice which was perceived to be most firmly established in the very agencies and professions designed to provide services to consumer survivors, whether it be a crisis service, medical and hospital services, employment and training services, or financial assistance. It was felt that the problem of prejudice is the single most important factor limiting the effectiveness of many agencies and individuals.

Education arose as an equally repetitive solution theme to counter both stigma and poverty. Across groups, consumer/survivors identified the need for education at the level of the consumer/survivor, the public, and the professional and recognized the power of the media and schools in effecting changes in perceptions. Participants identified two consumer/survivor driven strategies for changing stigmatizing attitudes. Both education and contact, or “putting a face to the illness”, were perceived as challenges to myths and misconceptions which participants felt were validated by personal experiences. Workshop attendance, presentations, and having a consumer/survivor forum at professional meetings and workshops were seen as providing non-consumers an opportunity to see the person behind the illness in addition to educating the audience and empowering the consumer/survivor.

Consumer/survivors also considered the possibility of protest as a strategy for change at the government level. However, participants also acknowledged that given the disempowering structure of the mental health system, the organization of consumer/survivors as a lobby or protest group was still in its infancy. Participants across groups invariably allocated the responsibility for protest in various forms to advocacy groups such as PACE and, on an individual basis, to patient advocates.

In addition to the problem of prejudice in limiting treatment efficacy, participants across groups identified a number of factors which influence the failure of community and hospital based mental health and social programs to meet consumer/survivor needs. Stories frequently arose related to 1) incorrect referral due to a lack of knowledge on the part of the referee, 2) no or not enough treatment due to program limits, waiting lists, failure to meet criteria, or inability to obtain a referral, 3) lack of care availability and continuity across all of the stages of illness, and 4) inflexibility or power and control issues within the numerous mental health services and support programs which include bureaucratic red tape and oppressive intake procedures. Problems were also frequently encountered as a result of the family doctor’s role as the primary gatekeeper for access to housing programs, social assistance, community mental health programs, medical care, vocational rehabilitation, specialists, and hospital admissions and other services.

Having a caseworker/manager, even an ineffective one, was perceived as an advantage across a variety of themes, particularly in negotiating the preceding access and continuity issues. The need for “true” case management was a frequent solution across groups. The

subject also arose in association with physician accessibility issues and with financial assistance, employment, and housing accessibility. Consumer/survivors provided a description of a “true case manager” as one who co-operatively assists the consumer/survivor in negotiating the entire system, advocates on their behalf, refers and manages involvement with other agencies, maintains the relationship in periods of wellness, and has the authority to allocate time which is relevant to the degree of need. Caseworkers were also perceived to offer particular advantages in times of illness in terms of “speeding up the system”, smoothing transitions, troubleshooting, and “getting you somewhere when there is inflexibility in the system”.

In addition to case managers and independent advocates, participants across groups frequently saw a role for the experienced consumer/survivor as trained peer counselors, mentors, or buddies. Noting the particularly stressful, confusing, and uninformed nature of initial contact with the mental health system, consumer/survivors saw a particular need for peer specialists in assisting newcomers in negotiating the system.

As with many of the solutions offered across the groups, attendance to the possibilities of peer counseling and mentoring has impact in many areas. Peer specialists, a peer-staffed regional hotline, the creation of a consulting forum, and affirmative action in education and employment, were related to improving treatment and program efficacy, eradicating stigma, acquiring economic security, and empowerment.

One of the problems is that they don't know there are lots of us already there but we're afraid to identify ourselves...prominent people with mental illness who come out can make a big difference...to us and to the public's idea of us...

Yeah, but you can lose your job that way...it's a catch 22

The government needs to get involved so there are more of us...

Affirmative action...

Yeah but what can you expect...(they) only just started to realize that people in wheelchairs need certain things at work and that's something you can see and understand...

I hear Nostradamus predicted that we would finally get equality in 3001...

Few positive changes were noted by consumer/survivors over the past five years although there was a general approval of the movement to community based care and a recognition of the growth of the consumer/survivor voice. A review of the earlier phases reveals a remarkable consistency in consumer/survivor experiences over time. As in the original study, stigma and poverty continue to be the primary barriers to good quality of life and care for consumer/survivors and the bulk of recommendations remain centered on

methods of replacing stereotypical and mythical images of the mentally ill. Inflexibility, a lack of consideration for individuality, transportation issues and complex bureaucratic intake procedures continue to hinder access to treatment and support programs as they did for consumer/survivors in 1993 and 1996.

They categorize you...

They put you in a box and they can't see you anywhere outside of that...

While the private housing market had improved for participants in the current study, problems with supported housing remain consistent and the same treatment issues arose in relation to hospital Approved Group Homes. As in the original study, current consumer/survivors frequently utilize a variety of community resources from food banks to educational programs and are generally satisfied with these services. Overall, the current discussions indicate that the areas of focus originally identified in Phase I continue to be relevant to consumer/survivors of the mental health services.

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Appendix I: Questions and prompts

Introduction and Question Format

Welcome! You are taking part in a group to identify solutions to problems you have encountered as consumers of the mental health system. Tonight's group is focused on the area of _____. We will be on a first name basis and although we will be recording the discussion, no names or identifying information will be attached to any report. Our group is scheduled to run until _____.

My name is _____ and I will be the moderator this evening. My role is to guide the discussion in such a way that we can cover the areas of interest. I'll be assisted this evening by (co-facilitator).

There are no wrong answers, only different points of view. You do not have to agree, but must listen respectfully as others share their views.

(Evaluation of group process questions and identification of new attendees at each group. Prompt for solutions for each identified barrier/problem)

Housing

Q: What are the choices?

Q: Does your housing meet your needs?

P: Is it adequate / inadequate? What makes a good place to live? What makes a bad place?

P: Has your living environment affected the quality of your life?

Q: What are the problems encountered in trying to find housing? What about keeping the place?

Q: How could these problems be fixed?

Q: What about supported housing?

P: Is this a good service – What makes it a good service?

P: Is this a poor service – What makes it a poor service?

Q: Where do you go to find help with housing problems?

P: Is this a good service – What makes it a good service?

P: Is this a poor service – What makes it a poor service?

Q: What's missing?

Q: Thinking back, over the past five years, how have things changed?

Financial Issues

Q: What are the sources of income for this group?

Q: Does your income meet your needs?

Q: What problems do you associate with your present income?

Q: Where do you go for help (in a financial crisis)?

P: Is this a good / poor service? What makes it good / poor?

Q: What has been your experience with applying for assistance?

P: What about staying on assistance?

Q: What has been your experience with finding and maintaining employment?

P: Are there barriers out there for MH Consumers/survivors?

Q: What would help you become more secure financially?

Q: Thinking back, over the past five years, how have things changed?

Hospital services

Q: Tell me about the circumstances that result in consumer/survivors being hospitalized?

P: Who brings the patient in? Why? How? Where?

Q: Are there problems with admission?

- P. What are the solutions? What works and what does not?
- Q: What is the quality of care for hospitalized patients on psychiatric wards or in psychiatric hospitals?
 - P. Are there differences among the hospital sites?
 - P. Who coordinates care?
 - P. Are patients safe and secure?
 - P. Is staffing sufficient?
 - P. Are professionals available?
 - P. What is the degree of patient involvement in care?
- Q: What are the problems with hospitalization? What are the solutions?
- Q: What about discharge? Are there problems?
 - P. Is there continuing care after discharge?
 - P. Is there referral to necessary services?
- Q: What about when a consumer/survivor is hospitalized for a non-psychiatric illness?
 - P. How do non-psychiatric wards deal with your mental health?
- Q: Do you think the closure of the LPH will be a good thing or a bad thing for consumer/survivors?
- Q: What special services will the regional hospital need in order to compensate for the closure of the LPH?
- Q: What can be done to support consumer/survivors if there is a bed or other service shortage?
- Q: What changes over the past five years can you comment on?

Mutual Support

- Q: What self-help groups or services are you familiar with?
 - P. Which are specific to mental health?
- Q: What are people's thoughts on the benefits of self-help groups and agencies?
 - P. Are they effective? Why/ why not?
 - P. What are the problems associated with self-help groups? What can be done?
- Q: Are there barriers for consumer survivors when it comes to self-help?
- Q: What about self-help groups related to specific diagnoses -are there gaps?
 - P. Is there a stigma attached to belonging to particular groups?
- Q: How can consumer survivors support those newly involved in the mental health system?
- Q: Can self help groups be doing more? What other services can they provide?
- Q: Thinking back over the past five years, what changes have occurred in the area?

Community Mental Health Services and other Community Resources

- Q: How accessible are community mental health programs to consumers?
 - P. Is there a wait?
 - P. Is getting a referral a problem?
 - P. Are there conflicts between programs?
 - P. What's good and what's not?
- Q: Are there advantages/disadvantages to community mental health services?
 - P. How do they compare with medically oriented psychiatric services?
- Q: What services would a good community mental health center have?
 - P. If you could take what's good about community mental health and leave out what's not good...
- Q: Has community mental health changed over the past 5 years?
- Q: What about other services to the community? Are there barriers in accessing public education?
 - P. Are training and education needs different for consumers?
 - P. What kinds of information and training could PACE offer?
- Q: What other community services are frequently used?
 - P. Other counseling services, substance abuse treatment centres, libraries, public transportation?
 - P. Any comments on these in terms of being a consumer?
- Q: How do these services and public places react to the consumer/survivor who is ill?

Social & Recreational Issues

- Q: What kinds of recreation and social activities does this group engage in?
- Q: What barriers exist for the consumer with regard to social activities and recreation?
P. Do illness or medication side effects affect your social life?)
- Q: Are recreational/social activities sponsored by groups like PACE or CMHA preferable to public events?
P. Are these sufficient?
P. What could be done to improve or expand existing services?
P. How can we interest other consumer/survivors?
- Q: Are there particular problems for consumer/survivors in friendship, partnership/marriage?
P. Do c/s seek out other c/s as friends?
P. Is there support for non-consumer friends, partners?
- Q: What can be done to improve consumer/survivor opportunities for recreation and social interaction?
- Q: Has this area shown any changes over the past five years?

Quality of Life

- Q: Can people tell me how their lives have changed since their illness?
P. How many take medication daily....
- Q: How has your illness affected your goals and dreams?
P. What do you see for yourself in the future?
P. Where do you see yourself in 10 years?
- Q: How does a relapse, such as a period of depression or mania, affect your day to day life?
- Q: What is your greatest fear related to your mental health?
- Q: What is the single most important thing you would need to make your life better?
- Q: What can be done to improve the quality of life of people with a mental illness?

Appendix II: About P.A.C.E.

People Advocating for Change through Empowerment (P.A.C.E.) Inc.

P.A.C.E. is a community-based, incorporated, not-for-profit organization operated by and for consumers/survivors of the mental health system. P.A.C.E. is committed to improving the quality of life for people who experience the misconceptions, prejudice, discrimination, and stigmas that are associated with mental illness.

GOALS AND OBJECTIVES

To advocate for human rights, systemic changes, and social justice.

To promote opportunities for consumer/survivor involvement in all levels of the mental health system.

To develop community partnerships.

To validate consumer/survivors' experiences and ensure their voices are heard.