

PEOPLE ADVOCATING for CHANGE through EMPOWERMENT

329 Waverley Street, Thunder Bay, Ontario

**SURVIVING IN THUNDER BAY:
AN EXAMINATION OF
MENTAL HEALTH ISSUES**

– Phase Two –

REPORT
of the
ACTION RESEARCH TEAM
October 1996

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INTRODUCTION

Origin of Project

In June 1992, concerns were raised at a Steering Committee meeting of the Ontario Psychiatric Survivors' Alliance – Thunder Bay Chapter (O.P.S.A. – T.B.C., (renamed *People Advocating for Change through Empowerment*, P.A.C.E.), that there had never been a study of the needs of consumers/survivors from their perspective in Thunder Bay. No attempt had been made to formally evaluate their views of the mental health system, community services, and overall quality of life. Following through on the concerns raised at the Steering Committee, a grant was obtained from Human Resources Development Canada to fund a pilot project, a qualitative¹ research study.

An “Action Research Team” was formed in October to investigate mental health and other related issues, from a consumer/survivor perspective. Members of the team consisted of consumer/survivors and community service providers with some experience in research. In preparing for the project, the Action Research Team developed a terms of reference to guide the research project (see Appendix One). An information matrix was also developed to assist the team in gathering information critical to forming the research process (i.e., what do we want to know, why do we want to know this, what do we already know, what kind of information do we need, who do we ask, and where do we go to find out?). The team worked on and adapted a list of assumptions for each study area, based on the information that the matrix generated (see Appendix Two). The team was responsible for facilitating all aspects of the research process, and reported progress of the project to P.A.C.E.'s Board of Directors.

Given the importance and immensity of the project, it was decided that the research should be conducted in two phases. The first study involved open-ended questions, using one-to-one interviews with thirty recipients of mental health services. “Surviving in Thunder Bay” An Examination of Mental Health Issues – Phase One” (P.A.C.E., 1993) was published in July 1993. The information in the report was a brief overview of what participants felt were the most pressing issues that impact on their lives. The findings from this research phase were intended to document the issues and trends that had emerged, and form the basis of study for the second phase.

A second grant was also obtained from Human Resources Development Canada to proceed with phase two, and complete the research project. This follow-up study, “Surviving in Thunder Bay: An Examination of Mental Health Issues – Phase Two,” involved using a focus group series to discuss the findings identified in the first stage of the research. The focus group meetings included discussions on the following topics: (a) Financial Assistance; (b) Housing; (c) Hospitals; (d) Crisis Services; (e) Public Awareness; (f) Mental Health Barriers; (g) Community Resources; (h) Non-Medical Health Services; (i) Social Recreation; and (j) Mutual Aid. Phase

¹ Qualitative research involves the collection of data or information (by means of open-ended interviews, participant observation, etc.) which will provide a description of the circumstances and conditions of the situation, community or problem as the primary basis for developing an analysis.

One of the research included chapters on “Ontario Psychiatric Survivors Alliance – Thunder Bay Chapter,” “Self,” and “Open Comments.” The Action Research Team observed that a large portion of the information generated from those chapters had been repeated in some other sections of the report. It was decided not to have focus groups for these topics for the sake of continuity and expediency.

The findings from both research phases are incorporated into this final report. The vast majority of this study involves systemic issues such as poverty, housing, discrimination, and problems with the mental health system. This report contains numerous issues that consumer/survivors of the mental health system encounter, and includes subsequent recommendations that P.A.C.E. and other groups, community services, and governments can act upon. Although the research focuses on the realities in Thunder Bay, many of the findings can be used for discussion and action in other areas of the province or country. It is anticipated that this study will serve to stimulate discussion, action, and improvements within the mental health system, and society itself.

METHODOLOGY

Phase Two of the research was designed to test the validity of the findings from Phase One and utilize a different research technique (i.e., individual interviews and group meetings). For this reason, in May 1994, the Action Research Team adopted a revised mandate (see Appendix Three).

The participants for the study were consumer/survivors of the mental health system. In the context of this report, a consumer/survivor is someone who has been, or currently is a recipient of mental health services (e.g., someone who has utilized a psychiatrist, psychologist, counsellor, community mental health services). The size of the focus groups varied from eight to twenty individuals, with the average size being between thirteen and fourteen people. In all, approximately forty-five individuals participated in Phase Two of the research. Several people who were interviewed in Phase One, also participated in the focus groups series.

Materials

- office space and supplies
- computer and printer
- bus passes
- pizzas and pop for meetings
- three cash prizes (\$50, \$100, \$150)

Method

The Action Research Team followed the guidelines in the research text by Barnsley and Ellis (1992) to assist with the planning of the research project. The team was also responsible for undertaking the following tasks to ensure the completion of the research project.

• Planning and Administration

The Action Research Team held meetings to further define the process for the study by revising the mandate, developing a work plan (including time-lines), defining the budget, and monitored the financial affairs of the project.

• Hiring of a Research Coordinator

The Action Research Team developed the job description and interview format to be used for the hiring process. The position of Research Coordinator was advertised in the Thunder Bay Chronicle Journal in February 1994. The applications were reviewed, and four individuals were selected to be interviewed. A Coordinator was hired in March, however, the researcher was unable to complete the job. Two of the other finalists were offered the position, but had other commitments. The process of advertising, interviewing, hiring, and training an individual is time

consuming. Rather than repeating the process and delaying the project further, two individuals from the Action Research Team assumed the responsibilities of the Research Coordinator.

- **Developing Focus Group Questions**

A set of questions was developed to stimulate discussion for each focus group. The questions were based on, and designed to investigate trends that had emerged in Phase One (see Appendix Four).

- **Recruitment of Participants**

Notices advertising the research were posted at P.A.C.E., Habitat, the Canadian Mental Health Association – Thunder Bay Branch, Lakehead Psychiatric Hospital, McKellar Hospital, and Alpha Court. Two Action Research Team members went to the Canadian Mental Health Association to explain the research to Club House members. Notices were also sent out to the P.A.C.E. membership.

- **Organizing the Focus Groups**

The sessions were called the “Let’s Talk Series,” and meetings were held at the P.A.C.E.’s office building. A schedule was developed for the focus groups. Two of the sessions had to be rescheduled due to poor turnouts. Therefore, the “Community Resources” and “Non-Medical Health Services” topics were combined and discussed in one meeting. The individuals who assumed the role of Research Coordinator, facilitated the focus groups and recorded the information on a flip chart. Each session began with a brief review of the research summary from Phase One (see Appendix Five). Cash prizes of fifty, one hundred, and one hundred fifty dollars were drawn randomly at the conclusion of the focus group series. The focus group series was completed during August and September 1994.

- **Data Analysis and Report Writing**

The raw data from the flip charts were typed word for word on a computer. The information was written into sentences, and organized into paragraphs according to subject matter. The findings generated in the “Hospital Services” and “Crisis Services,” “Public Awareness” and “Mental Health Barriers,” and “Community Resources” and Non-Medical Health Services” focus groups, contained very similar or related information. For this reason it was decided that these chapters should be combined in the final report as “Hospital and Crisis Services,” “Public Awareness and Mental Health Barriers,” and “Community Services.” The “Public Awareness” focus group also generated a lot of information regarding hospital services. These findings were reported in the “Hospital and Crisis Services” chapter. A “Quality of Life” chapter was added as all the focus group discussions indicated how the various issues affected their lives. The Data Analysis and Report Writing Team met many times to edit and revise the report, and developed subsequent recommendations. The report was proofread by an individual who was not involved in the research. The final revisions were made. The Board of Directors of P.A.C.E. reviewed the report and officially endorsed the document.

- **Follow-up Plans**

Phase Two will be distributed to numerous agencies, groups, politicians, and government offices who are stakeholders in the mental health system. The report is also available to the P.A.C.E. membership and any other community members and organizations upon request. A press conference will be held to announce the research and general findings. People Advocating for Change through Empowerment will endeavour to use “Surviving in Thunder Bay: An Examination of Mental Health Issues – Phase Two,” as a guide for advocacy and action.

Chapter 3

FINANCIAL ASSISTANCE

"It's always a struggle and it's not a very joyous feeling when you're downtown and you don't even have enough money to go for a coffee, you know."

(P.A.C.E., 1993, p.8)

Everyone in the "Financial Assistance" focus group was receiving a Disability Pension (Family Benefits Act – F.B.A.) through the Ministry of Community and Social Services (C.O.M.S.O.C.). The majority of the group said that their income is not sufficient to meet their needs. The previous research also indicated that many consumer/survivors felt that their income did not adequately meet their basic living needs (P.A.C.E., 1993). These results are supported by the current research.

The group said their income was not enough to afford quality food, clothing, and housing. Consumer/survivors often run out of food before the end of the month. Many individuals have to supplement their food supply by going to the soup kitchen, food banks, purchasing damaged goods, or attending group meetings where food is provided for participants. Many of the focus group participants indicated that they would starve if not for the food banks. Some people have inexpensive lunches at the Canadian Mental Health Association's Club House, where meals are provided for about a dollar. A person's income is not enough to have a healthy diet; this puts an individual at high risk for development of a variety of medical problems (e.g., malnutrition, depression). The vast majority of people also cannot afford to supplement their diet with vitamins.

Consumer/survivors generally cannot afford new clothes, and are often forced to purchase second hand clothing. If they do have money for new clothes, they can only buy the cheapest generic brands of clothing. This type of clothing is most often only available in "popular sizes." People who require extra large clothing are especially disadvantaged. Commonly, large sizes are only available at specialty clothing stores and are priced beyond the range that a person on F.B.A. or welfare can afford. Group participants said they were embarrassed to attend formal social gatherings such as weddings, because they had no decent dress clothes to wear. There are few recipients of assistance that can afford to dress to "societal standards."

The opportunity that consumer/survivors have to enjoy an active social life are limited (P.A.C.E., 1993). Luxuries like a vacation or social activities that the general population takes for granted (e.g., going to movies and dining out), is usually unaffordable for an F.B.A. or welfare recipient. This seriously limits a person's involvement with activities such as sports, dating, and developing relationships; which contributes to an individual's loneliness and isolation. Social activities are also restricted by transportation costs. Very few consumer/survivors can afford cars, and are left to rely on the transit system. Many cannot afford bus or taxi fares, and have to walk, bicycle, or stay at home. People who use the transit system are especially disadvantaged on Sundays, when bus service is limited, and on holidays when there is no service (see Social Recreation, p.27).

Some consumer/survivors are unable to open a bank account because they lack the proper identification. Group members felt that places like Money Mart or Rent To Own victimize the poor. Many individuals have to utilize the services of Money Mart and pay higher transaction fees than in a bank. Sometimes they cannot wait for the first of the month to cash their government or municipal cheque. Larger purchases like a stereo or television are unaffordable for most, as they cannot buy on credit or save enough money to pay cash. Such purchases can be made through retailers like Rent To Own, but it costs the impoverished considerably more. Someone with a decent income could buy larger purchases outright, or pay less interest somewhere else.

Most consumer/survivors find themselves in a difficult position when the money runs out before the end of the month. Many are forced to borrow money from friends. When somebody's F.B.A. or welfare cheque arrives, and debts have to be paid back, it puts more strain on the person's already stretched income. This often forces them to borrow again, and a vicious cycle of debt and repayment continues.

Consumer/survivors cannot afford decent housing. People are often forced to live in rooming houses, unless they have subsidized housing. Few can afford new furniture and buy it second hand, or do without. When moving, providing first and last months rent was a notable barrier to finding suitable housing. Many individuals with a mental illness do not have permanent housing, and live in shelters or on the streets (see Housing, p. 11).

The type of lifestyle that many people are forced into by living on a limited income affects their self esteem. Most individuals who socialize with consumer/survivors are also impoverished. Since there are so many people entrenched in poverty, it affects whom they associate with, and where. This has created a subculture of poverty among many consumer/survivors in Thunder Bay. People who are employed, including some friends and family members, often look down on consumer/survivors because they perceive F.B.A. and welfare recipients as abusers of the system. Participants in P.A.C.E., (1993) indicated that living on a limited income affected their self esteem.

Consumer/survivors' relationship with the Ministry of Community and Social Services (re: F.B.A.) and City Social Services (re: welfare) was characterized by the invasion of privacy, powerlessness, and dependence. All aspects of a recipient's financial affairs such as income, assets, bank balance, and available cash are well known by the recipient's worker. One focus group member said, "a person could starve while waiting." People receiving benefits are required to disclose a great deal of personal information to their workers. This process can be degrading, demeaning, and humiliating. It can be a very difficult, demoralizing, and lengthy process to apply for benefits or appeal an F.B.A. Denial of Assistance. Group participants felt that the forms are complex, and many of the questions are insensitive, intrusive, demeaning, and dehumanizing.

The group said their dealings with C.O.M.S.O.C. or welfare were intimidating and oppressive. They did not like being slotted into diagnostic categories, and felt that their benefits would be jeopardized if they were not labelled as "incurable and unemployable." Others complained of being shuffled around from worker to worker, resulting in lack of consistency. Sometimes

mistakes are made by the government, and recipients are overpaid. Recipients who are accustomed to poverty often will take advantage of the extra money when they get the chance. If the mistake is noted, people are penalized by receiving less money on subsequent cheques. Naturally, this makes budgeting their money even more difficult.

The quality of life of F.B.A. or welfare recipients is also affected by the limitations on medical services/benefits. Many medications are not covered by their drug benefits, and are priced beyond what a consumer/survivor can afford. Medical services that are not covered, or are only partly subsidized under the Ontario Health Insurance Plan (e.g., chiropractic care, dental surgery, etc.) are too costly for most people. Group members complained that once they brought their monthly drug eligibility card to one pharmacy, they could only deal with that pharmacy. They are not allowed to keep their cards. There was concern that the government and some physicians did not make it clear what medications are covered under the Family Benefits Act. It is difficult to know, or keep up with the services and medications that a person is entitled to under legislation.

Focus group participants who are on F.B.A. did not feel at all financially secure. A recipient can be cut off from their benefits or have it withheld for a number of reasons. One person had her benefits cut off because she was considered employable due to her education, without consideration for the limitations the illness had placed on her life. When someone is hospitalized, Disability Benefits can be cut or suspended during their time of admission, depending on the circumstances and at the discretion of their worker. This in turn, can jeopardize a recipient's housing. Recipients can also have their benefits cut or suspended because of temporary employment, or for having more than \$3,000.00 in the bank. One group member did not qualify for benefits because he had a coin collection and a few antiques. Sometimes consumer/survivors have to reapply for benefits because their psychiatrist or physician neglected to send the appropriate forms to the government. This lack of financial security causes a great deal of anxiety. Complaints about financial assistance eligibility and excessive government bureaucracy were also documented in P.A.C.E. (1993).

Some of the group members dislike the fact that their finances were under the complete control of social workers (i.e., trusteeship). No bank transactions were permitted to some consumer/survivors unless authorized by their social worker. In these cases, people complained that their social workers were concerned solely with controlling their finances, rather than teaching money management skills. "We are treated like children." This in turn encourages dependence on the system.

Participants indicated that they have little or no chance at living a fulfilled life and many are affected by a profound sense of powerlessness. Generally speaking, individuals felt that their small income made plans unattainable, and dreams impractical. Group members felt that they were only provided with enough resources to keep them where they are, while at the same time, creating employment for service providers and government workers. These feelings are legitimized in the control over people's lives by the government, agencies, social workers, and the medical establishment. These powerful influences readily cut services and benefits, rather than cutting back on areas like lucrative government salaries and expenses. Living in poverty is difficult enough itself, living in poverty with a mental illness makes survival far more difficult.

Participants said that getting a job would help them become more financially independent. However, many said they were afraid to go off F.B.A. because they would need high paying jobs with little stress to come out ahead. If they became ill and were forced to leave their job, the process of reapplying would create a great deal of anxiety. It can be difficult getting back on a disability pension (P.A.C.E., 1993). Some people who have been ill since their teenage years or younger have little or no job experience. This creates a Catch-22 situation. Suggestions of how participants thought they could become more financially secure, was the development of self-help groups to address financial and vocational issues and needs (e.g., resume writing, role-playing job interviews, and entrepreneurship). It was also suggested that a consumer/survivor business council be formed to be used as an information resource. Some group members felt that marriage, a better education, a computer, a car, better housing, winning a lottery, or receiving an inheritance would also help them achieve financial security. Past research indicated that consumer/survivors felt they could achieve financial independence through employment or winning a lottery (P.A.C.E., 1993).

RECOMMENDATIONS

- The government could provide employment incentives to encourage consumer/survivors toward financial security (e.g., start-up grants for small business, subsidies for businesses hiring F.B.A. recipients).
- A single disabled person on F.B.A. can only make \$160.00 per month. Any additional earnings will result in a deduction to their disability pension. The Ministry of Community and Social Services could provide F.B.A. recipients more incentive to find employment (e.g., increasing the amount of money an F.B.A. recipient can earn before their pension is affected).
- The process of reapplying for benefits after having been employed could be improved, making it easier for consumer/survivors to regain their benefits.
- Consumer/survivors who have successful careers in public service or business could share their experiences and skills in self-help groups.
- P.A.C.E. could explore developing a business to provide employment opportunities.
- Public education is needed regarding mental illness and the economic/social consequences of unemployment and poverty.
- P.A.C.E. and other agencies/groups (e.g., Canada Employment Centre) could work cooperatively to educate the business community about mental illness.
- Barriers to obtaining an education need to be addressed, such as with the non-flexibility of the educational system (e.g., attendance criteria, difficulties in taking time off if you become ill) and the associated stereotypes that prevent a person from going to school.

- The Ministry of Labour could bring legislation into effect that would allow greater flexibility for consumer/survivors to take leaves of absence at work while in an acute stage of their illness.
- P.A.C.E. could advocate for more flexible policies with banking establishments to allow people with limited income and identification to open accounts.
- P.A.C.E. could organize a community kitchen to teach members how to cook nutritiously and economically.

Chapter 4

HOUSING

“I have to lie to my landlord to get a place to live; like tell him you’re on disability, if it’s not visible or physical they don’t take you. Even slum lords won’t take you because they don’t want psychiatrically ill people in their building.”
(P.A.C.E., 1993, p.11)

Focus group participants were asked about their current and past housing situations. No participants in the group owned the property in which they were living. The groups’ accommodations included individuals living in supportive and/or subsidized apartments through the Lakehead Psychiatric Hospital, Alpha Court, Canadian Mental Health Association, Habitat, Lutheran Community Care Centre, and individuals in non-supported or subsidized rental arrangements. Some group members had been in supportive housing with Castlegreen Co-op Housing, Approved Homes and Homes for Special Care through the Lakehead Psychiatric Hospital. Others had rented room and/or board, while some lived with family or friends. One consumer/survivor in the group was staying at the Thunder Bay Shelter House. A number of group members had utilized emergency housing such as the Women’s Crisis House, Salvation Army Hostel and Shelter House. Others said they had been homeless, living in culverts, parkades, and park benches. A minority of group members said their housing was adequate enough to meet their needs. This is consistent with the previous research (P.A.C.E., 1993).

The majority said their housing situation did not meet their needs, due to the poor physical conditions and locations of some homes, as well as lack of security, privacy, and support. Similar results were obtained in Phase One of the research (P.A.C.E., 1993). The demeaning rules in supportive housing were also seen as a problem. Group members said their apartments were too small, hot/cold, noisy, and their “building was falling apart.” Some group members did not feel safe in their home because they did not have a private entrance, chains on the doors, or a smoke detector. One participant said that she felt isolated; while others said they enjoyed socializing with their neighbours. Several participants did not feel safe either because the physical structure of the building was unsafe, doors and windows did not lock, or people felt threatened by noise and fights in the downtown locations. One member did not feel comfortable being the only woman in a six-plex. In such situations, group members felt discouraged to socialize for their own safety.

In Phase One of the research, respondents felt living on a limited income forced them to settle for substandard living conditions (P.A.C.E., 1993). This offers strong support for the current findings. One group member said people on welfare or F.B.A. were seen as less deserving, and are expected to accept lower standards of living. It is difficult to find decent non-subsidized housing on F.B.A. or welfare. Consumer/survivors are limited in their housing options by the insufficient income. To save enough money for first and last month’s rent, is almost impossible (see Financial Assistance, p. 6).

Complaints were made regarding various housing authorities, their bureaucracies, rules and regulations. The Thunder Bay Housing Authorities, Habitat, Canada Mental Health Association, and Alpha Court all require their prospective tenants to answer, what are often viewed as,

intrusive and degrading questions. Some housing authorities require monthly inventory checks which invades the privacy of tenants. “You have to decide how much you are willing to compromise yourself.” Group members also felt that some people who have been labelled as “undesirable” or “difficult,” are kept at the bottom of waiting lists.

Lack of privacy was viewed as a major problem, especially for those in supportive housing. Several group members said that the Canadian Mental Health Association and Alpha Court support workers drop by without notice. There were complaints about Alpha Court’s practice of monthly apartment checks. Sometimes service or maintenance people enter an apartment unannounced, invading the privacy of tenants/clients. Cluster-unit tenants said they felt as if they were still in the hospital, due to the lack of privacy and having to share everything in the unit. People living in a private apartment enjoyed their privacy.

Group members in supportive housing were concerned about the quality of services that are offered. Often, the assistance offered in various supportive housing arrangements is not sufficient for tenants requiring 24 hour support. People questioned some of the staff’s counselling skills and the lack of consistency among staff. There are times when support is not available when the tenants/clients want or need it, unless there is an emergency. It was felt that some supportive housing workers manage the finances of some tenants’ money, without teaching the necessary skills to budget their own finances. Some group members said they were not accepted for whom they are, and some workers won’t allow people to think for themselves.

Many individuals who live in supportive housing felt they had to meet staff and agency expectations and fit into their system. Residents of supportive housing have limited options, either conform to staff and agency rules, or leave. It was felt that many of the services offered are not geared toward the individual, “if you don’t conform to their mould they may evict you.” Sometimes tenants/clients are not aware of, or do not understand all the rules and expectations of their tenancy, until after they have already moved in. A few participants felt the staff expectations were too high.

Living in supportive housing had varying effects on individuals’ quality of life. There were group members who felt too dependent, stifled, and confined in supportive housing, “it stifles me, it confines and obliterates the life in my soul.” One person was told that he would never make it in the “outside world.” A group member who was residing at Habitat said the support was good, while another person received supportive housing quickly after it was requested. Some participants in the Non-Medical Health Services focus group indicated that they benefited from supportive housing services. The earlier research indicated that a minority of consumer/survivors were satisfied with the support offered in housing programs (P.A.C.E., 1993). However, many consumer/survivors prefer to avoid supportive housing systems.

Group members were critical of the Lakehead Psychiatric Hospital’s Approved Homes and Homes for Special Care. Complaints were made about the home operators or “house mothers” who had been verbally abusive and neglectful. Group members who had lived in these homes said there was little freedom. Their daytime activities involved structured programming. The home life was also structured around unrealistic rules like bed curfews or turning the television off at specified times.

The participants said they had encountered several obstacles while trying to acquire housing. These barriers involved landlords, the stigma of mental illness, long waiting lists, and the excessive control housing authorities have over tenants. “People experiencing mental health problems can be treated with dread, suspicion, and loathing.” The previous research shows that many consumer/survivors were subjected to discrimination from landlords (P.A.C.E., 1993). The focus group members supported that landlords can be manipulative, greedy, and incompetent. Some landlords let their places get run down, while others won’t accept tenants who have pets. An individual’s past can be a barrier. If someone committed property damage while ill, it can affect the type of housing they can get in the future. Group members said the waiting lists for supportive housing are one to three years long, another member indicated having to wait for several years to get into Alpha Court. People who do not require a great deal of support are likely to stay on the waiting list for a long time. “You have to require a lot of support or the authorities won’t help you.” Long waiting lists were concerns that were also noted in the first research phase (P.A.C.E., 1993).

The group had several suggestions on how to improve the housing situation for consumer/survivors. The majority of the suggestions involved the attitudes of the staff involved, rules, structure of the various supportive housing authorities, availability of housing, accessibility, and the levels of support required. Some participants thought that improved accessibility to “rent geared to income housing” would be extremely helpful for people living in poverty. Quality housing in accessible locations would offer consumer/survivors better choices. If “rent to own” housing could be made available, it would be an option that may encourage increased personal empowerment and responsibility.

Overwhelmingly, group members want to be treated with dignity and respect, and not feel judged. Services provided for supportive housing tenants should be tailored to meet the needs of the person. When individuals recover from an illness and grow as persons, their needs often change as well. The level of support should be flexible because people want support available when it is needed. Consumer/survivors want to be supported by caring, sensitive, and friendly service providers who will make an effort to listen and understand. Focus group participants did not want the staff that they work with to place their own values, beliefs, and standards on them. It was felt that the rules and expectations for supportive housing tenants/clients should be more relaxed and individualized to allow for more freedom and personal autonomy (e.g., eliminate demeaning rules such as no overnight visitors, specified times for the television being turned off, curfew, bedtime, etc.). Staff and agencies need to respect the privacy of their tenants/clients. Most of the group felt that there are tenants/clients of supportive housing who would like to be more influential in the service delivery and administration.

RECOMMENDATIONS

- Housing Authorities could benefit from consumer/survivor involvement in service design/administration.
- Services should be tailored in partnership with individual tenants/clients to meet their changing needs.

- Quality housing options should be available to people living on a limited income in accessible, safe locations.
- Consumer/survivors should be aware of rules and regulations that many housing services expect tenants to follow. Housing authorities also, should ensure that prospective tenants/clients understand these regulations before a person moves in.
- Public education regarding mental illness is necessary to help change the prejudicial attitudes of some landlords.
- A comprehensive “in-service” training for housing staff could involve the following aspects:
 - consumer/survivor involvement in planning workshops and presentations
 - emphasis on developing and maintaining respectful relationships with service users (e.g., allowing tenants’ privacy, not being controlling or condescending, respecting tenants/clients’ values, beliefs, and choices, etc.)
 - teaching service providers the philosophy and practice of empowerment
- Clearer definitions for policies, procedures, accountability, and lines of communication within the housing authorities, would benefit service recipients and management.
- Home operators offering lodging to consumer/survivors through Homes for Special Care or Approved Homes should be screened more thoroughly to ensure that they are qualified.
- Information such as housing options, tenants/clients’ rights, and changes with legislation could be made more readily available to people.

Chapter 5

HOSPITAL AND CRISIS SERVICES

“Staff talk about patients and how crazy they are. No wonder there is such a stigma in the community.”
(P.A.C.E., 1993, p.15)

The information generated from the Hospital Services and Crisis Services focus groups was interrelated and consistent with one another. The chapters were amalgamated for this reason.

Focus group participants were asked of their experiences with psychiatric hospitals/wards, and the program and service quality. Hospitals that the group had utilized were the Lakehead Psychiatric Hospital, St. Joseph’s Hospital and the Smith Clinic, Thunder Bay Regional Hospitals (formerly McKellar and Port Arthur General), and out-of-town hospitals in Manitoba and Penetanguishene. The Lakehead Psychiatric Hospital was mentioned far more frequently than any other psychiatric facility. Most of the comments recorded were some findings that could also apply to the psychiatric ward at Thunder Bay Regional Hospital’s McKellar site. These included systemic issues such as the admittance procedures, adapting to the hospital’s environment, rules and regulations, poor attitudes of some staff members, and the associated stigmas that people with a mental illness endure.

Overall the group members were not satisfied with hospital services. However, there were some services and programs that were viewed as valuable. A few focus group members were pleased with the services they received from the Lakehead Psychiatric Hospital. The Social Work Department was valuable in assisting a person to find housing, budgeting for rent and groceries, providing information and referrals to other services. The Recreational Program was also praised by some, because of how they were treated by the staff working in the department. One participant said the Lakehead Psychiatric Hospital was, “a safe place where you can rest.” Some participants liked the Lakehead Psychiatric Hospital’s school, because they felt comfortable in the setting, and the program allowed for flexibility. General hospitals and 911 were viewed as valuable for the availability and accessibility of service during medical or psychiatric emergencies, and provision of information on medications.

However, the group was very concerned with the Lakehead Psychiatric Hospital’s programs, and the overall treatment effectiveness and service quality. Generally, participants had negative experiences as inpatients on psychiatric wards. Concerns ranged from being mistreated by individual staff members, to experiencing the powerlessness associated with institutionalization. The poor attitudes and treatment that patients received from some staff, was identified to be a significant problem. A participant’s feelings about psychiatric hospitalizations characterized those of the group, “traumatized, abused, used, degraded, controlled, disempowered, betrayed, felt more like punishment than help.”

Many common issues about the Lakehead Psychiatric Hospital were identified by focus group members. Complaints about the services included crisis services, admission procedures, and the actual experience of being an inpatient with all of the rules, regulations, and a lack of rights. Service availability and accessibility was another well noted concern. Certain services and

programs were viewed as ineffective and insufficient. These same issues had also emerged in Phase One (P.A.C.E., 1993).

Crisis services in the city were seen as diverse in terms of the number of resources. Services ranged from crisis lines and food banks, to more formal services such as emergency rooms and the Faye Peterson House. The following resources were identified by focus group participants as crisis services:

- Dew Drop In
- Children's Aid Society
- Lakehead Psychiatric Hospital
- Hospital Emergency Departments
- Aids Committee
- Depressive/Manic Depressive Support Group
- Canadian Mental Health Association
- Lutheran Community Care Centre
- Independent Living Resource Centre
- Faye Peterson Transition House
- Beendigan Native Crisis Home
- Physical and Sexual Assault Crisis Centre
- Vocational Rehabilitation (through C.O.M.S.O.C.)
- Alcoholics Anonymous
- Social Workers
- Telecare
- Alpha Court
- 911
- Shelter House
- Kid's Help Line
- Physicians
- Witness Protection
- Poison Control
- Salvation Army
- Detox Centres
- Food Banks

Crisis services were viewed as fragmented, uncoordinated, and unresponsive to the needs of consumer/survivors. This is supported by earlier findings (P.A.C.E., 1993). Accessibility and the overall service quality and effectiveness was very questionable. Some group participants felt the Lakehead Psychiatric Hospital could do more to encourage and facilitate the utilization of community mental health agencies/groups for hospital patients. Information and outside referrals could then be more readily available.

When talking about their experiences with crisis services, group participants spoke primarily about Lakehead Psychiatric Hospital's services. The hospital's Crisis Department is usually the first encounter a person has with experiencing the hospital's services, and some of the associated barriers and stereotypes.

Problems were very evident in obtaining crisis services of the Lakehead Psychiatric Hospital. This supports the findings in Phase One (P.A.C.E., 1993). Usually, individuals must either be a direct threat to themselves or another person to be able to see a doctor. Even when suicidal, people experiencing crisis have frequently been refused services. One person said he was "put on hold" when he felt suicidal. Another said, "If you phone them in the middle of the night, they tell you to come back at nine o'clock in the morning, they don't care and they refuse people" (P.A.C.E., 1993, p. 21). When trying to access the crisis department, participants indicated that they had been yelled at, subjected to derogatory remarks, and felt that they were wasting the staffs' time. This was said to be a very degrading and disempowering experience. The problems in accessing the crisis services were considerably more evident after regular working hours.

Group members believed that an “all encompassing” and comprehensive crisis service system would best meet the needs of consumer/survivors. A mobile crisis response component would help to improve the availability and accessibility for people requiring crisis services. A coordinated and collaborative approach including a range of service functions (e.g., 24 hour crisis lines, a “safehouse”) could divert or reduce the need for hospitalizations.

The assessment procedures used in the admitting/crisis department were thought to be callous, intrusive, degrading, and disempowering. A major complaint about the crisis department was the excessively long waiting period before there is an assessment by a doctor. When a person receives the service, a nurse goes through a comprehensive assessment. Some group members felt that several of the questions asked were irrelevant and insulting. Once individuals saw a doctor, they were asked the same questions again. This is very uncomfortable, redundant, and unnecessary practice for many consumer/survivors to go through, because situations vary. Group members were angry about how people in crisis do not always have the opportunity to see a doctor because they are sent away following the nurse’s assessment. Group members did not approve of the hospital’s method of conducting assessments.

If a person in crisis is admitted, staff members go through their personal belongings, record the possessions, and lock them up. Group members did not approve of their possessions being taken away. Some participants were adamant over having to wear hospital pyjamas. The actual procedures used for an admission were less of an issue that the manner in which it was conducted by particular staff members. When staff is callous and insensitive toward a person who is being assessed and/or admitted, it unnecessarily contributes to feelings of degradation and disempowerment.

Upon admission, the provision of information to patients regarding the hospital’s programs, rules, expectations, privileges, rights, or an orientation to the “routine,” is dependent upon the staff working. Once a person is on a ward, they are frequently left alone without support, and/or heavily medicated to the point where they cannot function. Overall, participants said that being hospitalized evoked feelings of fear; “fear of the patients and staff, the hospital environment, the associated stigmas, of not being discharged, and fear of the outside world.”

Group members found it difficult to adjust to the regimented and controlling environment of an institution. Patients must learn to make significant compromises to conform with staff and hospital expectations. It was described how participants felt being on a psychiatric hospital/ward, “upset, awkward, angry, disadvantaged, depressed, desperate, disillusioned, and suicidal.” Some said that they had been treated like prisoners, locked up or unable to leave the hospital grounds. Group participants expressed feelings of degradation and powerlessness as inpatients.

Participants felt pressured to “play the game,” and conform to hospital rules and treatment plans. If patients are “noncompliant,” repercussions may follow. Repercussions can include physical and verbal abuse (e.g., derogatory remarks, staff yelling at patients), being ignored, confinement in a “side room,” excessive or forced medication, and other forms of intimidation. Some group members who were in Thunder Bay Regional Hospital, McKellar campus, experienced a similar type of intimidation or abuse of power. The patients who are noncompliant are frequently sent

(or threatened to be sent) to the Lakehead Psychiatric Hospital. McKellar Hospital was also viewed as providing services to a “different class of patient” (i.e., less stigma than that of the Lakehead Psychiatric Hospital).

Group members were very critical of the lack of programming that is offered, particularly on the wards. The weekends and weekday nights are the time when many patients need to keep themselves occupied, not only the nine to five, Monday to Friday routine. The difficulties caused by a lack of meaningful and beneficial programs, is augmented by how little time the hospital staff have to spend with patients. Most of the patients just sit around and have nothing to do with the majority of their time.

There were also criticisms about the Lakehead Psychiatric Hospital’s Approved Homes, and Homes for Special Care. Complaints were made about the “House Mothers” (the Home operators) who run these homes. Some group members had been verbally abused. Most complaints, however, revolved around the house rules and expectations for living there. Participants felt that their freedom was limited and daytime activities involved structured programming. Rules such as bed curfews and turning off the television at specified times were seen as unrealistic and degrading.

Many group members had concerns about the quality of medical treatment and care that they receive from their physicians. The medical treatment that some group members received, fell far short of what they felt was required. Accessing a psychiatrist was seen as a barrier. Seeing a psychiatrist once a week for a few minutes at a time is insufficient for someone experiencing significant mental health difficulties. It was felt that some doctors prescribe medication too liberally, without providing their patient information and examining all the factors. Group members felt that they had been over-medicated, drugged unnecessarily and that their medications were changed too frequently, “... it was like being warehoused and drugged” (P.A.C.E., 1993).

Another concern was that in the course of an admission, a patient can be assigned several doctors. Every time somebody changes wards, there is a different doctor who is assigned. Patients also cannot choose which doctor they see, nor can they see their family physician. With doctors coming and going, and with patients moving from one ward to another, it makes continuity and quality care next to impossible. Often patients do not know who is responsible for their care, particularly when their doctor is unavailable. Some participants felt that it was confusing having so many staff members working with them. It is very unlikely that optimal therapeutic relationships can be established with such inconsistencies built into the system. Therefore, it was felt that further clarity about staff roles and responsibilities is required to improve the continuity and consistency of care.

Some physicians were reported as rude or indifferent toward their patients. The group participants felt that doctors tended to have records that reflected negatively on their personalities. The doctors rely heavily on nursing charts for information about their patients. Staff attitudes can be reflected through negative observations in the charting reports. “Normal personality traits have been interpreted as neurotic.” One participant said her doctor was

unsympathetic concerning abuse issues. People had been accused of faking a mental illness to get attention, while others had not received medical treatment for physical ailments.

The group overwhelmingly felt that the attitudes of many staff are degrading, disrespectful, and that patients are treated without respect and dignity. “People walk all over you,” “treat you like garbage.” Participants indicated that many of the staff are insensitive, indifferent, abusive, and condescending toward the patients. It was thought that these attitudes are evident in the interactions between staff and patients. “I was literally thrown out of the outpatients unit by a nurse who was yelling, screaming, abusive, and very angry...” (P.A.C.E., 1993). Earlier findings suggested that some consumer/survivors felt the attitude of professionals were improving (P.A.C.E., 1993), however, this was not supported with the current study.

Most of the participants complained that the staff “talk at you instead of with you.” Group members also believe that staff generally interact with staff, and seldom engage with the patients. Some of the staff are approachable, but generally most won’t engage in a conversation unless the patients asks to talk. “They just sit around and talk to each other and hand out our meals...” (P.A.C.E., 1993, p. 17). A group member praised the nurses who “break the rules” by talking with the patients. Participants felt that staff vented their problems on the patients. Former patients said that they were refused treatment, ignored, “played off against one another,” and treated as if their attempts to get help were just a form of attention seeking. Staff are supposed to be there to help the patient get well, but the participants felt that they were there more to provide employment for the workers. These issues were also documented in Phase One (P.A.C.E., 1993).

Focus group members were quite familiar with Thunder Bay’s Hospital Restructuring Plans with the likely closure of the Lakehead Psychiatric Hospital. Group participants were concerned that adequate and relevant community services are not going to be in place prior to the redeployment and/or closure of the Lakehead Psychiatric Hospital’s services. There was also anxiety over community-based services being uncoordinated, and not prepared to meet the needs for more services, if hospitals restructure and/or close beds. The group was under the impression that mental health reform (moving from an institution to a community-based approach) is driven more by economics than it is by improving service quality. Decreasing the number of hospital beds could jeopardize individuals requiring intensive and ongoing care.

RECOMMENDATIONS

Hospital Services

- Hospitals should provide opportunities for consumer/survivor participation on their Boards of Directors and on Advisory Boards. Services or programs (e.g., outpatients, recreation, and social work departments) should also provide the same opportunities.
- Treatment plans need to be developed based on a holistic philosophy. Individuals have issues in their lives that cannot be treated with medications (e.g., malnutrition, loneliness, etc.).

- Patients should be actively involved in their treatment and care with the directly involved staff members.
- Patients should be able to see their regular physician when in hospital, and have a choice about which psychiatrist will be overseeing their care.
- Lines of communication among all hospital staff working with a patient need to be clearly defined and explained to the patient as required.
- Hospitals should make information (e.g., hospital regulations, medications, community services) more accessible to patients. Staff could be more proactive to ensure that such information is distributed.
- Hospitals need to work more effectively with community mental health agencies, and consumer and family initiatives to help people with the move from the institution(s) to community. To ease this transition, and improve the person's opportunities or community living, effective service coordination, and follow-up are essential.
- The Lakehead Psychiatric Hospital should provide patients with more opportunities for on-ward recreation and social activities, particularly during the evening hours and on weekends.
- Services of the Lakehead Psychiatric Hospital should be governed by a Board of Directors that has full responsibility and accountability for the institution.

Crisis Response System

- The City of Thunder Bay should move toward an integrated and comprehensive crisis system that will meet the diverse needs of people experiencing crisis. The participation of consumer/survivors, service providers, and family members is essential for the service/system design, development, implementation, and ongoing evaluation of effectiveness and quality.

The Gerstein Centre was mentioned repeatedly during both Phases of the research as a preferred model for crisis response.

- A Mobile Response Team should go to where the person is (e.g., a coffee shop, person's home) whenever feasible.
- A "Safe House" could act as an alternative to institutional care and reduce the need for hospitalizations. Ideally, it would service 24 hours a day, seven days per week, with a stay of approximately 72 hours. Services could include individual counselling and support, group therapy and/or self help, information and referral, service coordination, follow-up, medication adjustments, and advocacy.

- A 1-800 crisis telephone line could offer 24 hour crisis support and intervention (e.g., mobilizing the Mobile Crisis Response Team) as necessary.

Simultaneously, a 1-800 prevention telephone line would offer emotional support to a person experiencing problems and provide information and referrals to appropriate services.

- The Crisis System could include a Walk-in Clinic where consumer/survivors can access service (e.g., prescriptions, support, information, and referral).
- A single governing body (i.e., a hospital Board of Directors) should assume responsibility and accountability for the delivery of crisis services.

Chapter 6

COMMUNITY SERVICES

“When I was in the L.P.H., I went down to the gas station to rent a video and when I went to sign it out, the man there said to me, ‘oh, you don’t look like one of those people.’”
(P.A.C.E., 1993, p.27)

The Action Research Team observed that the “Community Resources” and “Non-Medical Health Services” focus groups generated similar information. For this reason, the two chapters were combined.

The Community Resources and Non-Medical Health Services focus group participants were asked if they were satisfied with the community resources in Thunder Bay. Of the services that were discussed, the group had mixed reactions. They spoke highly of services during the “Non-Medical Health Services” focus group meeting, and were generally satisfied. The “Community Resources” group discussion also indicated that many services are valuable, however, they identified various limitations and barriers. In Phase One of the research (P.A.C.E., 1993), respondents thought that while some organizations could do more, they were generally satisfied with community services in Thunder Bay.

Focus group participants were asked to identify what they felt were the non-medical health services and community resources in Thunder Bay. The list of services is extensive and diverse. The majority of group participants had utilized many community resources in Thunder Bay; this is consistent with Phase One (P.A.C.E., 1993).

- Thunder Bay Shelter House
- Salvation Army Men’s Hostel
- Dew Drop In
- Half Way Houses
- Community Centres
- Smith Clinic
- Lakehead Regional Family Centre
- Dry Dances
- Balmoral Detox
- Habitat
- Physical & Sexual Assault Crisis Centre
- Lakehead Association for
Community Living
- Catholic Family Development Centre
- Parks & Recreation
- ARC Industries
- Thunder Bay Police
- Public Schools
- Confederation College
- Canadian Mental Health Association
- Royal Canadian Legions
- Women’s Crisis Housing
- Salvation Army Soup Truck
- Food Banks
- Alpha Court
- Crossroads
- Alcoholics Anonymous
- Narcotics Anonymous
- Self Help Groups
- Lakehead Psychiatric Hospital’s
Recreational & Social Work Dept.
- Libraries
- Avenue Two
- Restaurants and bars
- Lutheran Community Care Centre
- Family and Children’s Services
- Creighton Centre
- Thunder Bay Transit
- Vocational Rehabilitation
(through C.O.M.S.O.C.)
- Basic Job Readiness Training

Some group members thought the services offered by Alpha Court are beneficial because they address a number of different areas in an individual's life. Support is offered to clients in a variety of ways by teaching money management and life skills, providing counselling, an on-call line for emergencies, as well as some social activities. Other services noted were information and referral, and support in accessing community services. It was felt that Alpha Court helps some consumer/survivors become more independent and comfortable in social settings.

Thunder Bay Chapter of the Canadian Mental Health Association was given some positive reviews by the focus group members. The Club House provides a safe, secure, and comfortable environment where friends can be made. Programs that were viewed to be beneficial were the transitional employment program, social recreation, education unit, information and referral, summer camping, and conferences. Some group members said the Rehabilitation Action Program helps people with goal setting, community involvement, and making friends.

The Lakehead Psychiatric Hospital's Outpatient Recreation Program was praised by some group members. "There are some good recreationalists at the Lakehead Psychiatric Hospital." Concerns were raised that in an atmosphere of government cutback and fiscal restraint, recreational programs always get cut first. While these programs are beneficial for many consumer/survivors, there are many people who are shy or introverted, and tend to become nervous socially in large groups.

There were concerns raised regarding the Lakehead Psychiatric Hospital, Alpha Court, and Canadian Mental Health Association. The issues with these services included screening procedures, eligibility requirements for service, long waiting lists for supportive housing, receiving service when it is needed, lack of privacy, and some staff's attitudes (see Housing, p. 11). The Lakehead Psychiatric Hospital's services were viewed to be inefficient, with problems in most departments and patient wards. The attitudes of many staff members were identified as being a significant problem and barrier to receiving quality care and treatment (see Hospital and Crisis Services, p. 15).

Crisis and transitional services were recognized as valuable community services. Group members said that the Thunder Bay Shelter House is a valuable resource for the homeless and impoverished because food and shelter are provided. A couple of participants described their experiences with Women's Crisis Shelters as a "crisis themselves," however, it is recognized that not all Women's Crisis Shelters are characterized this way. One woman in the group said that while her basic needs were being met, she complained of how residents sometimes abused other residents, and some staff were unsupportive at times. Halfway Houses were viewed favourable by consumer/survivors because it offers a safe and secure environment, where individuals are encouraged to recover through group and individual therapy.

The majority of the participants were pleased with the services offered by the Salvation Army. The assistance that is provided was viewed as available, accessible, and consistent. There are a wide variety of services offered for the destitute and people in emergency financial need. Some of the services that are provided include, the soup truck, food baskets, shelter, clothing, information and referral to other services (e.g., legal advice, help finding a job and support), and

access to a doctor. The clothes available at the Thrift Shop are good, warm, and cheap. Alcohol is not tolerated on the premises, and they can refuse admittance to people who are intoxicated.

Habitat is a residence run by the Salvation Army. The group found the staff to be helpful in times of crisis, providing support for doctor appointments, assisting with medications, and holding Alcoholic Anonymous meetings. Support in achieving independence in areas such as banking, cooking, life skills, information and referral, education, and employment were also helpful. People learn to become more responsible, motivated, and overcome seclusion. Group members' only complaint was the long waiting list to become a tenant/client.

Group participants were not impressed with how they were treated at some churches. It was felt that churches in general should be more welcoming to consumer/survivors. One person felt that he had to fake religious beliefs to get food. Sometimes individuals in an active stage of their illness have been seen as possessed by demons. They are not possessed. They are probably hallucinating. Ministers and priests need to recognize a mental illness for what it is, and not define it in terms of theology. Participants felt that clergy would benefit from training in mental illness.

Some Community Resources were utilized by the group for recreation. Group members enjoyed the libraries, but complained about services not being available on holidays or Sundays. Similarly, the bus system of Thunder Bay was seen as inadequate and inefficient. Thunder Bay Transit was criticized by P.A.C.E. (1993) for not providing bus service on holidays. Some group members enjoy socializing at Legion bars. They said the staff are friendly and made them feel comfortable. Pool tables are available and the drinks are relatively inexpensive. Many consumer/survivors are isolated and lonely (P.A.C.E., 1993). Community services need to address the social needs of all members of society (see Social Recreation, p.27).

The Police were viewed as helpful to consumer/survivors. One group member was given a ride home when he was injured. He also was assisted when having to go to Detox or the hospital. When lost, another group member received a lift home, and was given five dollars. However, not all participants' experiences with the police are positive. One person complained that he was unnecessarily handcuffed. Generally, the group felt that the police require more training (e.g., how to deal with a person that is delusional or suicidal).

Group members utilized some community resources for educational purposes. One person said that he experienced minimal discrimination at high schools. The group spoke favourably about Confederation College and Redwood School, whose teachers were described as friendly, open, and receptive. However, there were some complaints regarding the strict upgrading completion deadlines. One participant had accessed the Basic Job Readiness Training Program, he was satisfied with the program, but felt it should be more visible to the public.

The participants were less satisfied with government programs (e.g., C.O.M.S.O.C.'s Vocational Rehabilitation). These services were described as unprofessional, excessively bureaucratic, political, uncaring, and impersonal. People are treated as if they are mere numbers. Group members complained of long waiting lists, strict rules of eligibility, excessive paperwork, and

mistakes made by the staff, such as errors made with people's cheques (see Financial Assistance, p. 6).

One individual complained about services to the impoverished. He acknowledged that while it is important to ensure that services like food banks are not misused, it is unfair that F.B.A. recipients are discouraged from utilizing these services. "It seems that food banks are not there to service the needy, but the desperately needy."

The group wanted more opportunities to meet new people and make friends. It was suggested that a drop-in, similar to P.A.C.E. or the Canadian Mental Health Association's Club House, be set up in the south ward. The group proposed the development of a "Mental Health Centre" that would be open in the day and evenings, where peers could meet and enjoy various activities. Some services the group would like to see in the centre would include meals, education, exercise classes, employment services for short term jobs, and community outreach. "It would be a place where consumer/survivors could feel worthwhile as contributors to the community." Group members suggested that nutritional counselling would be a benefit to them. Consumer/survivors would like help learning how to obtain a good diet while living below the poverty line. The development of a Mobile Crisis Unit was suggested during the "Hospital Services" and "Crisis Services" focus groups. Consumer/survivors want holistic services that will address all of their needs instead of focusing solely on medical aspects (P.A.C.E., 1993).

Aside from these practical suggestions affecting the lives of consumer/survivors, the group also would like to see more public education and professional training for service providers to address the issue of stigma and prejudice. Members of the general public, particularly adolescents, can be very rude and cruel to people with a mental illness, and anyone else who has a disability. Public education is required to help dismiss some of the stereotypes surrounding mental illness to decrease public fear, misconceptions, and ridicule.

RECOMMENDATIONS

- Consumer/survivor involvement in the planning/provision of community services that are initiated or expanded upon when hospital services close.
- The more frequently used community resources such as police, recreation, transit, food banks, and shelters could benefit from education about mental illness.
- P.A.C.E. could advertise community activities in their Thunder Struck newsletter with relevant information.
- P.A.C.E. could approach services for donations (such as free passes) so that members may become more involved in the community.

Chapter 7

SOCIAL RECREATION

“... because a person can only do what they can afford to do, and with the amount of money that I take in every month, recreation is a luxury.”
(P.A.C.E., 1993, p.29)

Social recreation focus group members were involved in a wide variety of leisure activities. This is consistent with the previous research (P.A.C.E., 1993). Many enjoyed outdoors activities such as camping, fishing, skating, cross country skiing, mini-putt, or visiting the parks (e.g., Boulevard Lake, Sibley, Ouimet Canyon, Waverley Park). Group members also utilized various facilities in the community like the theatre, Welcome Ship cruises, Community Auditorium concerts, and Old Fort William tours. Several group members attended socials, dances, parties, and picnics. Watching and participating in sports (e.g., hockey, baseball) was another favourite pastime. Others enjoyed playing games like cribbage, bingo, and pool.

In Phase One of the research, a number of barriers to accessing recreation were identified. The focus group data confirmed that limited finances and transportation costs were the main obstacles to participating in many leisure activities. Consumer/survivors cannot usually afford the price of admission to many shows/events. Bus and taxi fare is another additional expense that many find unaffordable. The transit system can be inconvenient if a person's destination is not on an established route. Sometimes a person relying solely on the bus system will have to leave an event early to accommodate bus schedules. Some people have difficulty arranging activities around work or school. The vast majority of consumer/survivors cannot participate in holiday activities because there is no transit service (see Financial Assistance, p. 6).

In Phase One of the research (P.A.C.E., 1993) consumer/survivors said their illness and the side effects of the medication also limited their social life. This was confirmed by the comments made by some participants in the social recreation focus group. Some group members felt uncomfortable attending places/events where alcohol is served. Other people felt uneasy in large crowds. Some individuals said the side effects of the medication (e.g., drowsiness, dizziness, disorientation, blurred vision, low energy) are a barrier as well. People who have been hospitalized for extended periods of time can become institutionalized, and are not used to being socially active.

RECOMMENDATIONS

- P.A.C.E., other groups, and agencies could coordinate social events and activities to reduce scheduling conflicts. Organizations could also plan activities together and share costs.
- Social events and activities could be planned for the beginning of a month, while people have money.
- P.A.C.E. should continue to provide its membership with activities that are cost-free (e.g., movies, dinners, dances) whenever possible.

- P.A.C.E. should do long-term planning of their activities (e.g., confirm events, determine financial resources and sustainability, and increase the involvement of the membership in the planning).
- P.A.C.E. could develop a fundraising initiative to sponsor activities such as recreation, yearly events, and conference attendance.
- P.A.C.E. could initiate a lobby to restore transit services on holidays.

Chapter 8

MUTUAL AID

“When I talk to people in regards to my problems, what I find out is that there’s an avenue to vent, and that’s healthy. To be understood you know, everybody wants to be understood...”
(P.A.C.E., 1993, p.30)

The “Mutual Aid” focus group was to discuss individuals’ experiences with self-help groups; what is beneficial or not, and what could be improved upon. Most of the focus group members had experience with various self-help groups, and identified a variety during the discussion.

- Emotions Anonymous
- Alcoholics Anonymous
- Narcotics Anonymous
- Depressive and Manic Depressive Support Group
- Acquired Immune Deficiency (A.I.D.s) Committee
- People Advocating for Change Through Empowerment
- People United for Self Help
- Assertiveness Training and Anger Management

This finding is consistent with P.A.C.E. (1993) where the majority of consumer/survivors utilized a wide variety of self-help groups.

Generally speaking, the group found the self-help experience to be beneficial for several reasons. Individuals had developed relationships and friendships, helping them become less isolated. Some group members said that “mutual aid” increased their self esteem, and felt empowered by their participation. Their involvement gave them more confidence by feeling equal with and accepted by the other group members. Self-help validated the reality of participants’ illnesses and gave people more confidence to stand up for themselves, and grow as individuals. Some participants said they had received practical advice from other members on how to cope with their problems. Attending these groups also provided some participants with more direction in their lives.

The quality of life of participants was improved by being involved with self-help. People received information that was relevant to their own lives (e.g., available community resources), and learned how mental illness affects others as well as themselves. It was important to develop new relationships with people who are understanding, so they may be called when support is needed. A few group members said that Alcoholics Anonymous meetings were an asset because it gives a person the chance to talk about their difficulties. Focus group participants said their involvement enhanced their social skills, and helped them feel more confident and comfortable being around others. Participants felt less isolated because self-help groups provided opportunities to express themselves in a supportive environment, where friends and family may not understand. These findings are consistent with Phase One (P.A.C.E., 1993).

Focus group members did indicate that there are some limitations with self-help or mutual aid. Some people may become too dependent on the self-help groups. Concerns were raised about individuals who are discouraged by fellow group members from seeking out professional help. In their participation in self-help groups, members were sometimes given incorrect information. Others complained about facilitators and/or group participants dominating and controlling the meetings. “What I feel not helpful is that a lot of time when you start expressing some of your concerns in your life, it ends up that you are talking about their problems” (P.A.C.E., 1993, p. 30). Another concern was that some A.A. groups tended to be prejudicial and non-receptive toward people with a mental illness/health problem. Therefore, participants suggested that groups take place in hospitals and/or agencies for people with both addiction problems and mental illness. It was acknowledged that while self-help or mutual aid has its problems, the overall experience is positive. This is consistent with previous research (P.A.C.E., 1993).

In Phase One (P.A.C.E., 1993), consumer/survivors said they would like to see self-help groups developed for people who have concurrent disorders (mental illness and substance abuse), to assist people in planning recreational activities, share information and experiences, and a council of all self-help groups was proposed. However, in Phase Two, the focus group participants were more concerned about employment and financial issues (see Financial Assistance, p. 6).

The group had some criticisms about People Advocating for Change through Empowerment. They felt P.A.C.E. should offer more services such as advocacy, public awareness, providing relevant information to members, self-help and open-discussion groups. The group wanted P.A.C.E. to utilize their resources effectively (e.g., the office/drop-in). Similar concerns about P.A.C.E. were identified in Phase One (P.A.C.E., 1993).

RECOMMENDATIONS

- Self-help groups could be started to assist consumer/survivors with regard to concurrent disorders and job search skills.
- The government and the mental health profession should continue to support the self-help movement.
- P.A.C.E. could explore ways to promote self-help and increase membership participation.
- P.A.C.E. could be offering more activities and better utilize the office facilities (i.e., renovate the basement and third floors).
- P.A.C.E. should determine and prioritize the most pertinent recommendations for follow-up and action in the context of long and short term strategic planning.

Chapter 9

PUBLIC AWARENESS and MENTAL HEALTH BARRIERS

"I lost a lot of friends when I ended up in the mental health system"
(P.A.C.E., 1993, p. 34)

"There's a stigma attached, my fellow workers don't really understand.
They've teased and criticized me."
(P.A.C.E., 1993, p. 31)

The Action Research Team decided that the findings obtained in the "Mental Health Barriers" and "Public Awareness" focus groups should be combined. This was preferred because the information generated by the participants either addressed the same issues, or was in some way either interrelated or consistent with one another.

The group members in both focus groups had plenty of personal experience with mental health barriers, and discrimination. This supports the findings in the prior research report (P.A.C.E., 1993). Consumer/survivors felt they were "pigeon-holed" according to the stereotype denoted by their illness. The groups said they felt misunderstood due to other people's ignorance about mental illness. People with more severe mental illnesses are often viewed as "simple minded." Usually, when people learn that you have a mental illness, there is an automatic stigma attached to the individual.

Phase One of the research indicated consumer/survivors felt public fear and misconceptions about mental illness are widespread in society (P.A.C.E., 1993). This finding was supported by the current study. There is public fear when you "come out of the closet." This fear involves individuals being viewed as violent and psychotic killers. Hollywood movies exacerbate the misconceptions that the public at large believes. Many graphically violent suspense and horror thrillers start with some deranged lunatic escaping or being released from an "insane asylum." Many people are afraid that somebody with a mental illness may lose control at any time.

Media sensationalism leads people to believe that consumer/survivors are dangerous and unpredictable, when actually, people with a mental illness are no more violent than the general public. The media reinforces these stereotypes in glorifying isolated incidents of violence committed by someone with a mental illness. This misinformation can mould and help to solidify the public's perception. There is already a perception among the general public that individuals with a mental illness will never be successful. One negative story can overshadow several stories of achievement. By and large, most consumer/survivors are intelligent and competent people, yet this is a scenario that is rarely portrayed by media. Many individuals recover or learn to cope with their illnesses and lead "normal lives." Unfortunately, the media focuses primarily on negative incidents and ignores positive achievements.

Group members felt the legal system is also partly responsible for the discrimination against consumer/survivors. Murderers sometimes receive lighter sentences if they plead "temporary

insanity.” This automatically implies mental illness and violence are synonymous, which is a critical misconception about mental illness.

Other causes of discrimination cited by the group include lack of compassion, strict religious morals, sexual repression, exasperation, fear, social and political barriers. Some people who experience mental illness lose their inhibitions and may exhibit what is perceived to be strange behaviour. These behaviours are sometimes observable in public, although are not typical of the type of behaviour you can expect from consumer/survivors. Many members of the general public believe otherwise. Hence, these perceptions become part of the stereotype of mental illness; misconceptions lead to discrimination and prejudice. The public is generally ignorant about mental illness, and people tend to fear what they do not understand. Group members felt people also have a tendency to want to be better than others. “Some people do not feel so vulnerable if they can feel superior at the expense of others.”

Consumer/survivors have been treated rudely and with indifference, and are subjected to discrimination (P.A.C.E., 1993). Often people don’t trust individuals’ perceptions and judgements. The general public, family members, and friends can be condescending and judgemental by stereotyping people with psychiatric disabilities. Group members noted that some of the general public are very patronizing and protective toward them. It was also felt that the society regards consumer/survivors as “leeches” on the system and “failures,” and that people with a mental illness will never be successful. Among the general public, it was perceived that teenagers were the most candid in their verbal abuses, and in some instances, friends and family.

Discrimination can take on many forms in various situations. Some group members complained about certain bus drivers that treat people with reduced passes with sarcasm. The group was also critical that bus fares for the general population increased by five percent, while reduced bus fares increased by 25 percent. Participants had experienced discrimination at border crossings. Someone said they were treated poorly when renewing a driver’s licence because they have an illness.

Consumer/survivors had misgivings about the ways they had been treated by social workers and staff affiliated with government services, hospitals, and the mental health system in general. This is consistent with the first research phase (P.A.C.E., 1993). Group members had complaints about the staff of various government agencies, such as the Ministry of Community and Social Services and Housing Authorities. Many service providers and government workers are suspicious about consumer/survivors “scamming” the system. Some group members said they were treated like children. Others complained they had no privacy from social workers and government officials. Consumer/survivors’ lives are open books to the authorities. “It feels like living under a microscope” (see Financial Assistance, p. 6).

Mental health barriers were evident in staff attitudes toward consumer/survivors. Participants were very critical of the Lakehead Psychiatric Hospital staff (see Hospital and Crisis Services, p. 15). One participant said the Canadian Mental Health Association’s Club House staff avoided consumer/survivors who were experiencing an acute phase of their illness. Group members felt that their peers were more supportive and understanding than service providers in general (see Community Services, p. 22).

The group said the situation could be improved. Several suggestions were made regarding the education of the general public, students, politicians, and bureaucrats.

RECOMMENDATIONS

- P.A.C.E. could promote consumer/survivor involvement in the training of service providers and board/committee members.
- P.A.C.E. could explore leadership training for consumer/survivors to participate in mental health reform by sitting on committees, public speaking, and advocacy. Leadership training could include conflict resolution, team building, government procedures, board/committee operations, and advocacy training.
- P.A.C.E. should continue to accept student placements (e.g., social work, nursing, social service worker) and conduct class presentations at Confederation College and Lakehead University.
- P.A.C.E. could look at providing education about mental health issues in schools.
- P.A.C.E. could produce an educational pamphlet for the general public.
- P.A.C.E. could host an open house annually for the general public, service providers, family, public officials, and politicians who could become better acquainted with P.A.C.E. and mental health issues.
- P.A.C.E. could become a better information, referral, and advocacy resource regarding mental health issues, service options, and individual rights (e.g., tenant rights, patient rights).
- P.A.C.E. could endeavour to obtain additional resources to support an educational campaign.
- P.A.C.E. could initiate a cooperative effort with other agencies and groups to address public education. Strategies of such an initiative could include the following:
 - workshops
 - presentations, participation on panels
 - an annual open house at P.A.C.E.
 - student placements
 - class presentations
 - mall displays
 - participation in Mental Health Week
 - radio and television interviews
 - production of an educational program for Shaw Cable, depicting the lives of consumer/survivors from a survivor perspective

- Educational teams could be developed to teach service providers, family members, educational systems, politicians, media, and the general public.

Chapter 10

QUALITY OF LIFE

"I lost a lot of friends when I ended up in the mental health system... being in the system is the most demoralizing thing that I have ever experienced, humiliating too!"
(P.A.C.E., 1993, p.34)

Throughout this research report, there are strong factors that impact on the quality of life of consumer/survivors of the mental health system. These issues are particularly prevalent in the Financial, Housing, Public Awareness and Mental Health Barriers, and Hospital and Crisis Services chapters. Many of the issues are interrelated. Poverty impacts on a person's living accommodations and lifestyle. The nature of an individual's illness or mental health problem can also interfere with opportunities for education, employment, and social relations.

Consumer/survivors' quality of life is profoundly affected by mental health barriers. Many individuals are afraid of what others may think of them, and feel misunderstood, alienated, patronized, and put down. Mental health barriers have adverse effects on consumer/survivors' self esteem. Some service providers have told patients or clients that they cause their own problems, and do not try hard enough to help themselves. Participants said that they feel dependent and controlled by the system, which is an incredibly disempowering experience. These kinds of experiences often leave individuals feeling depressed and interfere with their healing and personal growth. The effects of these barriers on a quality life were documented in Phase One (P.A.C.E., 1993), supporting the current findings. The first study (P.A.C.E., 1993) indicated that a few consumer/survivors benefited from dealing with mental health barriers by becoming more understanding about themselves, and others who may be less fortunate. However, this finding was not supported by the focus group participants.

"They seem to treat you like you have no brains at all."
(P.A.C.E., 1993, p.15)

Living in poverty affects all aspects of a person's life. Inadequate housing can lead to issues of safety, poor physical conditions, undesirable locations, and the absence of security devices. Many consumer/survivors live in noisy buildings without privacy. Others live in small hot/cold and dingy hotels, rooms, or apartments. When a person with some mental health problem lives in poverty (lacking food, clothing, and adequate housing), it negatively impacts on their mental and physical health.

"It limits what I can rent and what I can't and which location I can live."
(P.A.C.E., 1993, p.9)

Living on a small, fixed income also impacts tremendously on a person's ability to be socially active. Many social recreation opportunities (e.g., going to movies, or participating in expensive sports) are a luxury for most consumer/survivors, if not completely unaffordable. This in turn makes it more difficult for individuals to meet others and develop relationships. Many

consumer/survivors live in social isolation. Without a place to socialize with others, depression and hopelessness can become a part of a person's daily life.

"Poor food, bare necessities, your environment, who you hang around with, who you meet in those places. They're on the down and out and they're on the bum too."
(P.A.C.E., 1993, p.35)

Perhaps the most contentious issue or problem is the one of societal ignorance or discrimination. The lack of the general public's education about mental illness leads to misinformation or myths, and the associated stigmas. This in turn, contributes to the discrimination, marginalization, and abuse that consumer/survivors often endure on a daily basis. Individuals are frequently degraded and humiliated by others because they do not understand mental illness.

"When they hear you have a mental illness,
all of a sudden there is a very negative judgement against you."
(P.A.C.E., 1993, p.34)

Many consumer/survivors often feel reluctant to make new relationships, speak with people, or even go out in public because of the stigma. Some of the group members will not use the bus stop in front of the Lakehead Psychiatric Hospital, so that others will not see them going to the hospital. One participant said that her mental illness affected her credibility as a parent. Other participants indicated that prejudice and discrimination prevents them from obtaining education and employment, or other rights and entitlements that the general population take for granted.

"Well, number one is the stigma that is attached. I can accept the illness, There are times when I'm not sure other people can accept my illness, so I tend to avoid those people and stuff like that. My quality of life has gone down because of it."
(P.A.C.E., 1993, p.34)

There is a myth that consumer/survivors are not intelligent and are a danger to society. The media has sensationalized the incidences of violent crimes. If a person commits a heinous act, it is automatically assumed that the perpetrator must be "deranged or crazy." Often perpetrators will endeavour to get a lighter sentence by pleading "insanity." Most often the general public wrongly associates violence with mental illness. Such misconceptions only reinforce society's ignorance and contribute to the degradation and mistreatment of people who have mental health problems.

"Even if the person who does commit a crime is disturbed, it's really publicized and they are sure to let the public know this person was mentally ill. I don't think people who are mentally ill are any more dangerous than the general public. If anything, more passive."
(P.A.C.E., 1993, p.33)

Not only do consumer/survivors have to cope with mental health problems, but individuals also have to wrestle with a mental health system that is inadequate and not responsive. Many feel that they are only provided with enough assistance to survive. Individuals often felt oppressed

by social workers, nurses, and doctors who exercise their control. Consumer/survivors are often the objects of discrimination and abuse by the people who are supposed to be of help.

“If you’re good and do what they say, then they like you. If you do something against, then you’re the scum of the earth.”
(P.A.C.E., 1993, p.32)

Stigma, poverty, poor living conditions, limited opportunities for employment, education or recreation, and dealing with the mental system are all barriers that consumer/survivors must deal with. These obstacles have far reaching effects on a person’s quality of life. If everyone in society was to experience the effects of living with a mental illness, recipients of mental health services would be treated with more dignity by the systems, and society in general.

RECOMMENDATIONS

- P.A.C.E. should conduct or initiate a research project to measure the impact of the reforming mental health system (i.e., the effectiveness, quality of life of consumer/survivors).

APPENDICES

Appendix One

TERMS OF REFERENCE

Mandate of the Committee

To guide the process of the Action Research Project in evaluating mental health services/issues in the City of Thunder Bay, from a consumer/survivor perspective.

Goals and Objectives

- Report progress to the Ontario Psychiatric Survivors' Alliance – Thunder Bay Chapter's Steering Committee (later to People Advocating for Change through Empowerment's Board of Directors).
- Develop a work plan for the project.
- Hire a Research Coordinator and provide guidance and assistance as required.
- Develop subcommittees as required to ensure the tasks of the research are completed.
- Assist with the development of interview questions and format, and focus group sessions.
- Monitor the budget for the projects.
- Monitor and evaluate the projects on an ongoing basis and upon completion.
- Review, analyze, and discuss the information and findings of the research.
- Develop recommendations based on the research findings.
- Develop strategies of how the final reports will be presented to the community, and identify "a target group" for the research.

Responsibilities of Committee Members

- Meetings will be held as frequently as necessary, a long-term commitment is desired.
- Members will be needed for subcommittees (e.g., for hiring, data analysis).
- Make a commitment to work together as a team.

Appendix Two

ASSUMPTIONS - PHASE ONE -

Financial Assistance

Poverty causes many problems. Survivors often live in poverty due to unemployment. Job creation and training are needed to promote employment. Any incentive to go out and earn an income is hampered for people on Family Benefits Allowance because if they earn money, their pension is cut back. Another problem caused by poverty is that it harms the individual's sense of self respect and the respect from others. A third problem is that people are discriminated against financially, as they lose their pension if they are hospitalized for thirty days or longer.

Housing

Current conditions that survivors have to live in are terrible. There is a lack of affordable housing, and shelters don't solve the problems of poverty. These conditions pressure people to turn to the system.

Health Services

Poverty impacts on a person's health. Some people on medication are sensitive to particular foods. Services needed are availability to vitamins and co-op food stores.

Crisis Services

These services are viewed as completely inadequate.

Community Resources

There are a number of problems in the area of community resources, for example, uncoordinated services, lack of understanding mental illness and ignorance of the issues, and "passing the buck."

Social Recreation

People on limited budgets do not have many options for social or recreational activities. This lack of money and options creates barriers for people. Additional barriers are the community's attitudes and individuals who, for various reasons, are in isolation.

Mutual Aid

Mental illness stigmas hinder survivors from reaching out to others. People are in isolation and need to be reached; more support is needed in this area.

Public Awareness

A major societal problem is the presence of prejudice and stigma, and the lack of understanding in the community in regard to survivors and mental health issues. More education is required to break the barriers.

Mental Health Barriers

Mental health barriers include such issues as transportation, stigmas and attitudes, lack of information and services, long waiting lists, non-individualized services, patronization, and a lack of alternative services.

Appendix Three

MANDATE

- Provide an opportunity where consumer/survivors may express their stories, concerns, and opinions regarding their experiences with the mental health system.
- Obtain and document information regarding what consumer/survivors see as the issues and concerns with the mental health system.
- Provide P.A.C.E. with future direction and action (i.e., for education, lobbying, and advocacy).
- Clarify and understand the findings of the first research report.
- Make visible the findings of the research to consumer/survivors, service providers, and government.
- Identify the specifics of issues (re: what the problems are and positive areas).
- Determine credibility of the Phase One research findings.

Appendix Four

FOCUS GROUP QUESTIONS

Public Awareness

1. Based on your experiences, how have you found the general public's reaction to you; how were you treated?
2. Based on your experiences, how have you found mental health professionals' reaction to you; how have you been treated?
3. Often survivors are subjected to prejudice and discrimination. What has been your experience?
4. What do you think are reasons people discriminate, stigmatize, stereotype, and are prejudicial?
5. What do you think are the causes of public fear?
6. How do prejudice and discrimination affect your quality of life?

Crisis Services

1. What do you think are the Crisis Services in Thunder Bay?
2. Which of these services have you most accessed and how frequently?
3. In what ways did these services meet your needs?
4. In what ways did these services not meet your needs?
5. What kind of a "crisis service system" would best meet your needs?
6. What training/expertise, qualities, qualifications, characteristics, etc., do you think "crisis staff" would require to do a good job?
7. What other opinions do you have regarding crisis services?

Hospital Services

1. What hospitals have you most often utilized?

2. How does it feel (has it felt) to be in a psychiatric hospital/ward?
3. Do services and treatments that hospitals provide meet your needs? If no, what services and why? If yes, what services and why?
4. Of the services that you have identified as inadequate, what needs to change for these services to be more helpful?
5. What else would you like to tell us about hospitals?

Social Recreation

1. What leisure or recreational activities does this group like to participate in?
2. How does your financial situation hinder you from participating in these activities?
3. How does transportation hinder you from participating in these activities?
4. How do other barriers or limitations hinder your participation in these activities?
5. What other recreational activities would you want to participate in or see organizations like P.A.C.E. offer?
6. What else would you like to tell us about social recreation?

Housing

1. What types of accommodations does this group utilize at the current time?
2. Does your housing meet your needs? Is it adequate? If it isn't adequate, tell us why. If it is, in what ways?
3. What barriers have you encountered in trying to find housing?
4. What have been your experiences with supported housing? How can supported housing meet your needs?
5. How has your living situation or environment affected your quality of life?
6. What would improve the housing situation in Thunder Bay? What kinds of housing are lacking and needed?
7. What else do you want to tell us about housing?

Mutual Aid

1. What experience have you had with self-help groups?
2. What makes self-help beneficial and why?
3. When is self-help not beneficial and why?
4. What kinds of self-help groups would you find beneficial?
5. How has self-help/peer support affected your quality of life?
6. What else would you like to say about self-help and/or peer support?

Non-Medical Health Services

1. Name the non-medical health services in Thunder Bay.
2. What non-medical health services have been beneficial to you?
3. In what ways could these services be changed/improved to better suit your needs?
4. What new non-medical health services would you like to see offered?
5. What else do you want to tell us about non-medical health services?

Financial Assistance

1. What are the sources of income for this group?
2. Does an F.B.A. or welfare income meet your basic living needs? If not, in what ways?
3. What have been your experiences in applying for F.B.A. or welfare, and/or remaining on assistance?
4. What barriers are associated with being on a limited income?
5. What would help you to become financially secure or independent?
6. How does being on a limited income affect your quality of life?
7. What else do you want to say about financial assistance?

Community Resources

1. Name the community resources in Thunder Bay that you have utilized.
2. Are you satisfied with the community resources in Thunder Bay? Why or why not?
3. What additional resources do you feel are needed?
4. What else do you want to say about community resources?

Mental Health Barriers

1. What have been your experiences with prejudice and stigma in Thunder Bay?
2. Have you ever been subjected to degradation, abuse, or ridicule?
3. What can be done to improve people's attitudes?
4. Have other people's attitudes affected your quality of life?
5. What else would you like to say about Mental Health Barriers?

Appendix Five

OVERALL SUMMARY - PHASE ONE –

Financial Assistance

While some respondents' financial stability is more secure through employment or support from family members, most respondents indicated that they are on a limited income such as Family Benefits Allowance. Financial stability influences a person's entire well being and quality of life. It affects their social life, plans for the future, and ability to obtain or maintain financial independence. It also affects a person's self esteem and sense of pride.

Housing

Housing emerged as a major problem area for survivors that causes particular concern. It is a problem primarily because of limited income. Specific issues were limited choice of housing (which usually forced survivors into poor quality accommodations), the complicated and drawn-out process of seeking housing, the lack of support available in the search process, and the shortage of assistance with the responsibilities and demands of daily living. The housing issue is further compounded by having to interact with housing authorities, landlords, and other professionals. Issues surrounding "supportive housing" included waiting lists, occupancy rules, having to regularly see social workers, and having to deal with the bureaucracy of supportive housing administration. All these concerns add to the stress that arises in the ordeal of searching for housing.

Hospital Services

Responses indicated that all of the city's hospitals were utilized for mental health reasons. Apparent negative attitudes and inadequate job performance of most staff at the various facilities were identified as barriers to receiving proper care and treatment in hospitals. Suggestions proposed for how improvements could take place were: retrain staff, expand services, offer alternative treatment services, and extend services into the community. Some optimism was present with occasional positive comments about staff and treatment.

Health Services

Several survivors felt that health services focused primarily on the "medical model" and that holistic, supportive, and educational approaches were neglected. While some survivors had good experiences when dealing with staff, the majority expressed concerns about how they have been treated. These complaints ranged from poor staff attitudes to accusations of abuse and neglect. Some survivors indicated that these experiences had harmed their sense of self. Respondents

were divided on their opinions concerning efforts that agencies have taken to improve services, and expressed several ideas about what services they would like to see offered.

Crisis Services

The main finding that emerged from the Crisis Services section was that the city's services were, for the most part, unsatisfactory and in need of improvement. The most prevalent complaints were of being talked to and treated in an uncaring, condescending way, and being refused service. These complaints were overwhelmingly attributed to prejudicial and unprofessional staff attitudes. The main improvement suggested was to have staff that are more qualified.

Community Resources

The types of community resources identified by respondents were quite diverse ranging from sports facilities to social and governmental organizations. A number of suggestions were made as to what additional resources were necessary in the community, such as expanded transportation services, and organizations that provide more services in the areas of education, employment training and placement, counselling, and leisure-time activities. Positive and negative comments emerged in regards to interactions with other people when using community resources.

Social Recreation

A wide range of services and programs were utilized, such as the Canada Games Complex and independent forms of leisure activity like going for walks and watching television. Many survivors said that they would like to participate more in social recreation, but their involvement is limited by financial and transportation barriers. Other survivors feel socially isolated either because of illness or not feeling comfortable in social settings.

Public Awareness

The general public and people working in professional fields have negative attitudes toward individuals who have mental illness; this is evident through prejudice and discrimination. There is a strong element of public fear that is based on such things as ignorance and misconceptions. This impacts on survivors' lives in terms of having to deal with stigma, stereotypes, and non-acceptance.

Mental Health Barriers

Biased attitudes were the prevailing factor when dealing with services and the general public. Non-acceptance, degradation, and prejudice were cited as being typical of the attitudes expressed

toward survivors. The media reinforces these public fears and attitudes. Survivors indicated that these attitudes impinge upon their sense of self and their quality of life. This in turn affects areas of their life, such as relationships, finding employment, or having the financial stability to meet their basic living needs.

REFERENCES

Barnsley, J., Ellis, D. (1992). Research for change: Participatory action research for community groups. The Women's Research Centre: Vancouver, B.C.

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

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.

We invite any questions or interests you may have with this research report or in People Advocating for Change through Empowerment.