

PEOPLE ADVOCATING for CHANGE through EMPOWERMENT

329 Waverley Street, Thunder Bay, Ontario

“Staff talk about patients and how crazy they are.
No wonder there is such a stigma in the community.”

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

– Phase One –

“It wasn’t bad when I didn’t give a damn about myself.
But now, I’m giving a damn about myself and it is hell.”

Report of the Action Research Team

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TABLE OF CONTENTS

Chapter		Page
	Acknowledgements	i
1	Introduction	1
2	Methodology	5
3	Financial Assistance	8
4	Housing	10
5	Hospital Services	16
6	Health Services	19
7	Crisis Services	23
8	O.P.S.A. – T.B.C.	25
9	Community Resources	29
10	Social Recreation	31
11	Mutual Aid	33
12	Public Awareness	35
13	Mental Health Barriers	37
14	Self	41
15	Open Comments	45
16	Overall Summary	47
	Follow-up Plans: Phase Two	50
	References	51
Appendix A	Interview Questionnaire	52
	About P.A.C.E.	57

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., now renamed *People Advocating for Change through Empowerment*) that there had never been a study of the needs of psychiatric survivors¹ from a survivor perspective in Thunder Bay. No attempt had ever been made to formally evaluate survivors' views of the mental health system and community resources.

Following through on the concerns raised by the Steering Committee, O.P.S.A. – T.B.C. obtained a grant from the Department of the Secretary of State to fund a pilot project, a qualitative² research study of psychiatric survivors in Thunder Bay. The Action Research Team, a standing committee of O.P.S.A. – T.B.C. was formed on October 20, 1992 to begin work on the project. The membership of the Action Research Team consisted of survivors from the membership of O.P.S.A. – T.B.C., and a few individuals with some expertise as service providers in the mental health field. The committee agreed upon the following areas of study: (a) Financial Assistance; (b) Housing; (c) Hospital; (d) Health Services; (e) Crisis Services; (f) O.P.S.A. – T.B.C.; (g) Community Resources; (h) Social Recreation; (i) Mutual Aid; (j) Public Awareness; (k) Mental Health Barriers; (l) Self; and (m) Open Comments.

Based on the above areas of study, the following assumptions were identified by the Action Research Team.

- a) **Financial Assistance:** Poverty causes many problems. Survivors often live in poverty due to unemployment. Job creation and training is needed to promote employment. Any incentive to go out and earn 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 respect for self and the respect from others. A third problem is people are discriminated against financially because they lose their pensions if they are hospitalized for thirty days.
- b) **Housing:** Current conditions that survivors have to live in are terrible. There is lack of affordable housing and shelters don't solve the problems of poverty. These conditions pressure people to turn to the "system."

¹ For the purpose of this study, P.A.C.E. defines a Survivor as anyone who has been or is currently a consumer of mental health services and/or utilizing the services of a mental health professional (i.e., psychiatrist, psychologist, counsellor, etc.)

² 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.

- c) **Heath Services:** Poverty impacts on a person's health. People on medications are sensitive to particular foods. Services needed are availability to vitamins, and co-op food stores.
- d) **Crisis Services:** These services seem to be completely inadequate.
- e) **O.P.S.A. – T.B.C.:** The organization is a vehicle to show that survivors are not helpless, but quite competent. The group also serves as a voice and advocate for survivors, it acts as a link for changes, it involves people helping each other, and plays a role in education. It was suggested that the group needs a drop-in centre.
- f) **Community Resources:** There are a number of problems in the area of community resources, for example, gaps in these services, ignorance of issues and lack of understanding, un-coordination of services, and 'passing the buck.'
- g) **Social Recreation:** People on limited incomes do not have many options for social or recreational activities to participate in. 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.
- h) **Mutual Aid:** Mental illness stigma hinders survivors from reaching out to others. People are in isolation and need to be reached. More support is needed in this area.
- i) **Public Awareness:** A major societal problem is the presence of prejudice and stigma, and the lack of understanding in the community in regards to survivors and mental health issues. More education is required to break the barriers.
- j) **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 lack of alternative services.

Note: Hospital Services and Self sections were later included as additional study topics.

On November 10, 1992, the Action Research Team developed the following objectives for the study.

- a) To provide an opportunity where survivors may express their stories, concerns, and opinions regarding their experiences with the mental health system.
- b) To show that survivors of the mental health system are capable of assessing the mental health system.
- c) To obtain and document information about what survivors see as being the issues and concerns with the mental health system and to provide O.P.S.A. – T.B.C. with direction

and action (for lobbying, education, advocacy, identifying gaps in services, and developing alternatives).

- d) To clarify and understand the findings from the research and to make follow-up plans.
- e) To make visible the findings of the research to survivors, services providers, and the government.
- f) To provide employment opportunities for survivors interested in doing research.

After developing the above objectives, the committee also established a time line and budget that was formally approved. A hiring sub-committee was formed to hire a Research Coordinator. The position was advertised, applicants were screened, and a suitable candidate was decided upon.

On January 18, 1993, the Action Research Team adopted the Terms of Reference for the study.

Mandate of the Committee

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

Goals and Objectives

- a) To develop a work plan for the project.
- b) To guide and support the Research Coordinator.
- c) To develop sub-committees and guide as required.
- d) To review, analyze, and discuss the information and findings of the research and to provide ongoing evaluation at each stage of the process.
- e) To monitor the budget for the project.
- f) To report progress to the O.P.S.A. – T.B.C. Steering Committee.
- g) To write an evaluation report of the overall project leading to a follow-up plan.

In addition, the responsibilities of committee members were identified as follows: (a) to try to attend monthly Action Research Team meetings, (b) to commit to of six months upon conclusion of the project, (c) to commit to work together as a team.

This paper is a report on the pilot study. Some noteworthy trends became evident in the study. It is difficult to determine the validity of the results with a sample size of only twenty-eight. A

follow-up study is planned using focus groups.³ Hopefully, this research will illustrate the problems of the mental health system, and stimulate efforts to improve the quality of life of survivors in Thunder Bay.

³ A focus group is a group of people who share some common interest who gather to discuss, debate, analyze, and/or evaluate issues and concerns on the subject of their mutual interest.

METHODOLOGY

Participants

The participants for the study were thirty survivors. Some of the participants came from the O.P.S.A. – T.B.C. membership, while others joined in the study through notices posted at Alpha Court, the Lakehead Psychiatric Hospital (L.P.H.), the Canadian Mental Health Association – Thunder Bay Branch (C.M.H.A.), McKellar Hospital, and Habitat.

For the purpose of this study, the term “survivor” will be used. A survivor is defined as anyone who has been or is currently a consumer of mental health services and/or utilizing the services of a mental health professional (psychiatrist, psychologist, counsellor, etc.). Participants were assured that confidentiality would be maintained, and the information gathered through the interviews would be used solely for the research study. Two interviews were not used for the study because those participants were too ill to answer the questions coherently at the time.

Materials

- a) Word processor and printer
- b) Interview Guides
- c) Three portable tape recorders
- d) Office supplies
- e) Flip chart

Method

The Action Research Team followed the guidelines in the research text by Barnsley and Ellis (1992) to assist them in planning the project. The efforts of the Action Research Team, various sub-committees, and the Research Coordinator included the following responsibilities.

- a) **Planning and Administrative Tasks**
The Research Coordinator worked with the Action Research Team and sub-committees of the team to facilitate the research process. The team developed the budget, a time line for the study, the terms of reference, and research strategy. The team, with the help of the Coordinator of O.P.S.A. – T.B.C., directed the finances of the study.
- b) **Developing the Information Matrix⁴ and Interview Guide**
A sub-committee was formed to develop an information matrix based on the areas of concern determined in the October meeting. The sub-committee met on numerous

⁴ An Information Matrix is the basic pool or cluster of information that gives the rest of the research its form; it is the origin, the starting point of the research process. It is information on the basic questions of research such as: what do we want to know?, why do we want to know this?, what do we already know?, where do we go to find out?, who do we ask?, what kind of information do we need?

occasions and produced a draft interview guide on February 5, 1993. The draft was presented to the Action Research Team for input. Care was taken to ensure that the questions were worded objectively and without bias. The Action Research Team accepted the final form of the interview guide on March 24, 1993.

c) **Hiring of Interviewers**

Another sub-committee was formed to hire three interviewers. It was agreed that the interviewers should ideally be survivors, have post-secondary education, and have experience in committee work and with the mental health system. The committee felt that if the interviewers were themselves survivors, then the participants in the study might be more inclined to share their experiences. The committee advertised, screened, and interviewed various applicants until three were selected on February 26, 1993.

d) **Training of Interviewers**

The Research Coordinator and a committee member trained the successful applicants. Training involved reviewing interview skills, developing familiarity with the interview guide, and role playing mock interviews. Specific instructions were given to the interviewers to maintain objectivity in their job and strive to be non-influential toward the participants' responses.

e) **Recruitment of Participants**

It was decided that the pilot study would ideally require a minimum of 30 participants and all participants would be psychiatric survivors. The Action Research Team decided to promote the study by obtaining permission from the L.P.H., McKellar Hospital, Alpha Court, Habitat, and C.M.H.A. to post notices asking for participants. By March 24, 1993 only seven participants had volunteered for the study. It became evident that a more proactive recruitment campaign was necessary. An employee of the C.M.H.A. and a member of the Manic-Depressive Support Group were asked to promote the study among their membership. The Action Research Team decided to offer a cash incentive to boost participation; three cash prizes of \$75, \$50, and \$25 were offered. The study was again promoted on March 26, 1993 at the third anniversary party of O.P.S.A. – T.B.C. The number of volunteers recruited by April 22, 1993 had increased to 22. Eight additional people from the O.P.S.A. – T.B.C. membership agreed to participate, this brought the group size to a total of 30.

f) **Conducting the Interviews**

The interviewers were responsible for arranging their own interviews. A covering letter was presented to the participant prior to the interview, explaining the purpose of the study. The interviews then proceeded with the interviewers posing questions from the interview guide. Each interview was recorded on a portable cassette recorder. Interviews were then transcribed. Interviews began in April and were concluded in June of 1993.

g) **Data Analysis**

A sub-committee was formed to analyze the data. The committee met for the first time on May 25, 1993. The analysis of the data began as the transcripts of the interviews became available. Different committee members took on the responsibility to analyze the

different topic areas covered in the interview guide. The committee members reviewed all of the transcripts, looking for commonalities and trends in the data. Data analysis was concluded in November.

h) **Writing the Report**

The research process was longer than anticipated. The Research Coordinator's contract had concluded, therefore, two members of the Data Analysis sub-committee and the Coordinator of O.P.S.A. – T.B.C. took on the task of preparing a comprehensive report on the pilot study. Another member of the research committee served as the editor. This group cooperated in revising drafts of the report which eventually led to its final form.

i) **Follow-up Plans**

The Action Research Team will endeavour to test the validity of the findings of the pilot study and explore the issues further through the use of focus groups. Recommendations will follow with the conclusion of the next study.

Chapter 3

FINANCIAL ASSISTANCE

This section focused on the financial situation of the respondents. The vast majority of respondents were on Family Benefits Allowance or some kind of financial assistance. A small number of respondents were employed or had received an inheritance. Some respondents had their incomes subsidized by other family members. Overall most respondents felt their income did not adequately meet their basic needs, such as food, clothing, and shelter.

‘It barely meets my needs. You know how most people are trying to break out of the poverty level, well if I could make it out of the poverty level I’d be happy.’

‘It is hard to ma nage.’

‘I don’t buy groceries unless they are on sale. I have to be careful. I don’t drink or smoke. I buy second-hand clothing.’

‘Well, I have to go that C.M.H.C. for lunch because my financial situation is so terrible that for 75 cents, I need the cheap meals there.’

Beyond basic living needs, respondents noted that being on a limited income also affected their ability to have a social life or plan for the future.

‘I can’t go to movies, I don’t go on trips and I’d like to go on a vacation.’

‘Well, it feels like you’re always struggling, 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.’

‘Very limiting, you can’t do much for entertainment so that’s why you’re so secluded. You can’t go out much because you don’t have the money for entertainment and stuff like that.’

The constant struggle of surviving on a limited income had taken a toll on respondents’ self-esteem and personal pride.

‘I sometimes feel guilty that I’m not providing for my needs, but I can’t work and I sometimes feel badly about that.’

‘It wasn’t bad when I didn’t give a damn about myself. But now, I’m giving a damn about myself and it is hell.’

“I don’t think I could stand being on this income for the rest of my life, it would drive me crazy.”

What made living on a limited income even more difficult were the policies and limitations imposed by the funding sources. There was no incentive to work because if a person earned more than \$160 in a month their pension was reduced, and they had more than \$3,000 in assets, the pension was completely cut off. Another complaint pertained to the difficult process involved in returning to a pension after having worked.

“There is no incentive for people to get off a disability pension and so back to work. You’re only allowed to earn \$160 a month, then they start deducting off your disability.”

“I had to go through three or four medicals to get back on benefits so it’s a hassle.”

Respondents felt financial independence could only be achieved through employment or by winning a lottery.

Chapter 4

HOUSING

The respondents were asked to comment on the various living situations they had experienced.

The most common type of accommodation was an apartment. Other living situations included: staying with friends or relatives, owning or renting a private or subsidized home, renting in a rooming or boarding house or hotel, boarding in a private home, placement in a group home, renting in a co-op house (i.e., C.M.H.A.), living in supportive housing (i.e., Alpha House), living in foster homes, staying in the hospital, and living on the street.

The most common problem experienced by respondents in regards to housing was renting on a limited income. Respondents felt a limited income restricted their housing choices and they often had to settle for substandard living conditions.

“... the problem is getting something in decent condition that you can afford.”

“It limits what I can rent and what I can't and which location I can live.”

“I've had some poor housing, yeah. I've had basement apartments such as, uh, no heat... It was about 50 in there. My stuff was freezing. I couldn't even sleep there. Yeah, I've had one, like a room in a rooming house, that wasn't too bad, but there was problems. I've had, um, lived in a family home where there was drinking within, with the husband, and I ended up drinking myself. So, it hasn't been very good until recently when I got into my place. It's one bedroom and it's very clean and very nice.”

“It's not a very nice place to stay. It's not a well equipped building, in fact, it may be illegal as far as the fire code goes. It's not in a very nice neighbourhood and frankly we're stuck there.”

“Mostly rooms [for housing]. They should have better housing for the people on limited income.”

One respondent had a particularly notable quote on the effects of living in poor housing:

“... there's like a stigma around the low rentals; once they find out that that's where you're from, that that's where you are staying, it's almost like you're branded as a certain individual or certain kind of individual... if you wind up living in a rat hole and you wake up every morning it's like you're in the same dive, you go to bed every night you're in the same place, you start to lose the joy of life, you

lose the spark that makes you want to do something and you start to slack off and then little by little hygiene goes, then your eating habits go and next thing you're right back where you started off, you know you're just as bad as you were before you got help."

Respondents commented on the difficult process involved in finding housing. Often, attaining housing turns out to be a difficult, time-consuming process because of the multiple stages to work through, such as applications and waiting lists. Having to seek out housing without help from anyone was described as a burden which causes stress.

"Problems I have had [with housing] is, it is really hard finding apartments. For the last one, I was in hospital...the social worker never helped me at all. I had to search myself and had to pay Home Sweet Home. It took about a month to find a place. This last place also took a while, doing it on my own, walking all over the place."

"...it took me seven years to find my own place, a very slow process. I basically took what I could get because I had no choice. That or I'm out on the street."

"Try to get a subsidized apartment in Thunder Bay. Unless you're involved with C.M.H.A, you might get lucky but you try to get subsidized housing in Thunder Bay, forget it. You're on a two year waiting list to start with...It's been over two and a half years now and they never called us once, not one single time. I know that because I have an answering service. Finally, decided to investigate it and find out what the heck is going on. No one has called us, this is after a year on the waiting list. (They said) 'Oh well, we tried to contact you people numerous times and we chucked your file out about three days ago.' We sat on the waiting list for a goldarn year and those idiots chucked the file out, nobody tried to contact us at all."

"[I was on the waiting list]...about four, five months. I put an application in and four or five months yeah. But, I've put applications in where I've been waiting, and waiting and waiting... The reason that I got in fast, I think relatively fast, is because of the need. Because I was literally on the streets and so they considered me a priority, an emergency priority eh and so I think that's why I was accepted."

"They have a waiting list of six months to a year. I don't have that kind of time. I need a place to live now, not in six months. A house for two people, two bedrooms."

When respondents were asked how landlords, housing authorities, and professionals treated them, the responses were divided.

“The housing people have been great, no trouble at all. They are willing to accept proposals from us and everything. ...I proposed that we get a four-plex or something. We haven’t done it, but they were willing to look at my proposal.”

“Just fine...they all accepted me. They knew I was on a disability pension... didn’t know why and didn’t ask! I had nothing to do with the housing authorities. The first place with the rooms, that was kind of a dump-off place for people from the hospital. The social worker just dumped me off. The next week, the worker dropped me off. I didn’t know anyone. This was my first experience in Thunder Bay after being in the hospital for the first time.”

“The landlord tends to speak to me in a tone that you might use in speaking to a three year old or to someone who is severely retarded.”

“Rough, very rough. They don’t see things my way. I don’t see things their way. That is just how it goes. If you leave me alone, I will leave you alone.”

“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 living in their building.”

When asked if any form of in-home support was available to them, some respondents mentioned support was obtainable, however, most felt they had no formal support services available for them.

“Okay, um, there is a support, I don’t utilize it, but there’s a, they have started up a support group for people who are having trouble making the transition into a new place, you know, a lot of, some people have never lived on their own before and they’re having trouble adjusting so there’s a support group starting to help people learn to adjust to being on their own.”

“For me right now, there is none available.”

“Care is that they mow the lawns front and back in the summer and if anything breaks down inside the house, they come and fix it. Not always on time or right away, but it depends on the degree

of seriousness that it is, but care and support, there's no support. This is just regular housing."

"I just have somebody come once a month looking out, seeing how I am doing."

A few respondents said they received informal support from friends, neighbours, or relatives.

"Have aunts and uncles I can call on. My sister helps, we shop for each other."

"Just what I want. Just my own support system I have to build up."

"Just support through friends."

"My dad lives two blocks away and he picks up the cat food for me...I pay for it, but he picks it up every month usually. If I am too tired, I get him to pick me up some milk and a few groceries... my sister lives in Fort William...she has been doing things for me like mailing letters, picking something up for me and I will pick something up for her and we visit, we exchange the money and whatever. I guess in a way that relates to my living here because it is so convenient. I can go to C.M.H.A. if I need to."

"This is a small community. The community as a whole is very supportive. When I was going crazy last year, they knew what was happening with me and were very careful with me, and then when they felt I needed to go to the hospital, they called the ambulance. It was my friends on the board that put me into the hospital."

Respondents expressed an interest in formal supportive housing,⁵ but mentioned various barriers that affected their ability to utilize these services.

"We got that through Alpha Court...It's low rental, so it's geared to my income. I mean, I tried to get into there before and I was on a waiting list off and on for about four to five years."

"I could have got into Habitat...I was supposed to be interviewed to go into Habitat but I just don't care for it...[because] there's no drinking at all. I still drank, so therefore, I mean I couldn't drink in there...and I didn't want social workers prying anyway in my life. I knew I'd drink again...even when I do quit, I know I will, might, drink again. I find it very hard to maintain sobriety. So far, I've lasted a year and a half sober through A.A. at any one time."

⁵ Supportive Housing is housing that provides support services to the people living there, helping them acquire and maintain various life skills of independent living.

‘I was on the list for a while. I would not take it because the locations are just stupid for people who cannot afford to take a bus every day. It is so far to go shopping or do anything.’

Respondents who are in supportive housing find these services valuable, but maintain goals of living independently.

‘[The support provided] It’s adequate for now. Like I realized that I needed support in, uh, money management and I’m getting that. I’m getting all the support I need...my worker, he helps me with my budgeting, with my money management. I see him once a week, you know, probably be once a week for a little while and then I’m going to try to get him down to maybe once a month too, after a while.’

‘I’m very fortunate to have this place [supportive housing]...it’s because of the new initiatives that the development is taking now towards people with mental illnesses. They’re giving them the support now that they need like housing, how to manage your budget and how to shop and they’re teaching us skills. I guess they’re listening to that old Japanese saying...that says, ‘Give a man a fish, feed him for a day; teach a man to fish and feed him for a lifetime.’ You know, if they just look after us and not really do anything, but if they teach us how to manage our own lives then in the end they’re going to be saving money by emptying the hospitals because we can look after our own lives given the proper skills.’

‘My present situation? Well, the housing, the apartment is nice, the furniture is nice, everything is nice, except, you know, you have to meet a worker once a week, you know, and talk with him and what-not, and being the independent person that I am, I have a hard time, you know, meeting the person. I like to come and go as I please and, you know what I mean, like to be independent, but I guess if I want the housing I gotta play by the rules you know. I guess it’s a small price to pay, you know, like you gotta do the dance when, you know you don’t get something for nothing, you know. Sure, I got it nice, but I think what I’d like to see eventually is I could become independent and move out of the supporting part of the housing and get another apartment in the same building, but of course when that happens all this furniture stays behind, everything stays behind. All I do is get an empty apartment.’

Other respondents were more critical of supportive housing.

“We also applied to Habitat. They promise you the moon and deliver you nothing, absolutely nothing. My wife, whom I had just met, needed housing. They did an application form. Basically she was taken to an apartment, shown an apartment and told ‘you’re on the top of the list now because you require housing immediately’ and all this. Well, it’s ridiculous. About two weeks later [the hospital] released her into the community without housing. When she went to see them, they had lost the file, misplaced the papers or something. So here this woman was out in the community with no support, no housing; she ended up at the Women’s Shelter.”

“...the hospital would practically force her [the owner of a supportive group home] to take in people who were really, really sick just to get them out of the hospital and it would stress out everybody in the house, all the other patients would get stressed out too...they don’t cover when they stick you out in the community, they don’t cover emotional needs, they just cover food and clothes. That’s all that matters.

A suggestion was made for the formation of a housing assistance group.

“But there has to be some form of rent control or landlord and tenant control, some place where a person can go to find a nice decent place, I’m not talking about a Taj Mahal, I’m talking about four walls, you know, and safe.”

Chapter 5

HOSPITAL SERVICES

In this section respondents were asked to comment on what type of hospital services they used. We were interested in how satisfied respondents were with these services and how they could see these services improved.

When respondents were asked which hospitals they used, all hospitals in Thunder Bay were mentioned, as well as, a few out-of-town hospitals. The Lakehead Psychiatric Hospital and McKellar were the most frequently used facilities. Respondents accessed a variety of services at the L.P.H. including: outpatient services, counselling/therapy, crisis intervention, admissions, and the pharmacy.

The majority of respondents were dissatisfied with hospital services.

“They seemed to treat you like you had no brains at all.”

“Staff talk about patients and how crazy they are. No wonder there is such a stigma in the community.”

“They’ve got a professional ego.”

“They let everything go on, they’re apathetic. They dole out medications without eyes, they don’t really observe the real person.”

“I would like to see hospital services offered where people would feel comfortable going to them. Some way there’s a communication gap between patients and doctors.”

“They don’t give you information a person needs.”

“They don’t do their jobs anymore.”

A few respondents maintained that they were satisfied with hospital services or at least felt they were improving.

“I find them helpful and friendly in there.”

“They are very friendly people there. I like the food in the hospital.”

“I don’t know if it’s me or the system, I find psychiatrists are treating me with more respect.”

‘I’m not sure why, but the last few times that I have been to the hospital I’m treated with a lot more respect than I used to be...’

The respondents had a wide variety of suggestions for improvements in hospital services. The following is a sample of the major trends.

a) Improve Staffing

‘Retrain staff.’

‘I would like to see more of the staff that are in there, better staff, staff that understand where people are at.’

b) Expand Existing Services

‘I think there needs to be more than one patient advocate...one advocate for a whole city, where there is a large population of psychiatric patients, is not enough.’

‘I think there should be more and better programs for victims of abuse.’

‘More beds, more transitional housing, allow people to get out of the hospital, to be in a safe, structured environment...they must be allowed to become functional up to the limits that they can.’

c) Implement Less Formal/Traditional Services

‘I’d like to see some kind of safe house. There’s a really good crisis service in Toronto called the Gerstein Centre...it’s non - medical. I’d like to see something like that here.’

‘Walk -in clinic...just designed for people with psychiatric illness.’

‘Some place where you could get your medications adjusted without so much hassle.’

d) Move to Increasing Community Services

‘More community care and something that suits emotional needs instead of physical and biological... 24hour emotional care.’

‘Extension of programs that are already in effect...community support services out of location away from the L.P.H. I think that would be helpful.’

“I think it should be better located. At least more accessible. To me going to the L.P.H. is a problem... decentralize the thing, diversify it...”

While respondents were dissatisfied with hospital services and suggested a variety of improvements; they were evenly divided on their opinions of the people providing the service. While some respondents found staff “polite” “caring” “helpful” and “friendly” others found staff “very cold” “inadequate” “uncooperative” and “mean.”

Chapter 6

HEALTH SERVICES

In the Health Services segment of the interview respondents were asked for their general impressions of the health and support services available to survivors.

Respondents identified a wide variety of health and support services in the community. The health services that survivors were aware of included: Telecare, L.P.H., Selkirk Hospital, Physical and Sexual Assault Centre, Wife Assault Help Line, Faye Peterson Transitional Home, Women's Centre, St. Joseph's Hospital, McKellar Hospital, Adult Children of Alcoholics, Catholic Family Development Centre, District Health Unit, Ministry of Community and Social Services, O.P.S.A. – T.B.C. (P.A.C.E.), C.M.H.A., New Foundations Club House, Thunder Bay Manic Depressive Support Group, Friends of Schizophrenics, doctors, and psychiatrists. Individually, however, respondents could only name a few of these services.

The majority of the respondents reported they had been treated poorly by health services staff. Respondents' complaints ranged from poor attitudes to reports of abuse and neglect.

‘I had a doctor sexually harass me.’

‘They just sit around and talk to each other and hand out meals. And they do charting based on what? I have no idea... I never opened up to them because there was no, there was no kindness there, no compassion or understanding.’

‘You would hear their frustrations over things. I found that was a bit odd. They were not careful in venting their opinions about themselves, about their bosses, and the system. They should have a forum to do that and they should not do that in front of patients.’

‘In the past, I found they're just out to use you for their personal growth. They don't give a hoot about you.’

‘People should be allowed to question their doctors and their physicians and their psychiatrists without being made to feel that they're stepping in an area they don't know. I don't want to be talked down to. I don't need someone who is condescending to me.’

‘...in isolation I heard about a lot of people they wouldn't allow to go to the bathroom and they would end up peeing on the floor and this was going on to this year...one individual was not allowed to go to the washroom and they kept her there for so many hours without being able to relieve herself. I think that is very indignant and is very criminal.’

“...there were not only patients, but staff, molesting women, male staff or patients molesting women...I could understand the patients because they were ill, they were sick, I was sick. I could never understand what happened on two or three occasions to me personally, molesting. I say molesting. I think if anybody massages your body or touches your body without your permission is, especially when what you consider to be your private parts and things like that you know.”

While the majority of respondents reported negative experiences with health services staff, some respondents noted that they were well treated.

‘I have found the system and the people who work for the system to be very helpful.’

‘I have two fine doctors, a good psychiatrist and a good family doctor, this doctor does not push any points with you when he gives you a prescription, he explains.’

‘I found them generally very helpful, very receptive.’

Respondents noted how their experiences with health services affected their sense of self in a negative way.

‘They won’t let you use the nursing station phones, so if you don’t have a pay phone or you don’t have quarters, you’re done for. Now they don’t sell cigarettes or tobacco in the canteen. Well then you gotta find somebody that’ll go. But you need a level to get to the canteen. They take your clothes away. They put you in pyjamas... it strips away your identity.’

‘You know, we’re not all crazy. We don’t all see the boogie man around the corner. Some of us have legitimate complaints. But if you’re always told, ‘Oh you’re over reacting,’ you know, ‘You don’t know what you’re talking about,’ or stuff like that, after a while you start to believe that yeah maybe I am. There are some doctors who don’t know, you know, an oesophagus from an asshole.’

‘Medical records at the L.P.H., when I read them over I thought, ‘Gee, I didn’t have a friend in the world because they all seemed to have such a low opinion of me...’

Several respondents felt health services focused solely on medical issues but non-medical, holistic, supportive, and educational approaches were somewhat lacking and needed to be addressed.

“...it was like being warehoused and drugged. I was drugged for depression and the drugs made the depression worse. They didn’t look into the cause of my depression. They automatically figured it was a chemical imbalance in my brain.”

“...first I would say look after the person’s basic needs like compassion, loving, caring, and support rather than medication. You know, look after their basic needs like loneliness.”

“...I believe that more emphasis should be placed on preventative services, teaching people how to prevent from being ill, not wait until they get ill and then do something. But teach them skills like good nutrition, activity in the community, how to be a productive member in society because that creates self esteem when you know that you’ve been productive during the day and go home and you can say you did something today that was a benefit to somebody.”

“It’s fine to switch to community programs, but the people with mental health problems I’ve come across have too much time on their hands and are alone too much and if they had supportive people around them all the time, the better off they’d be.”

Respondents had several ideas on services they would like to see offered. Respondents reported survivors needed to be educated as to what services were available and how to access them.

“I think there are a lot of ex -patients who are out in the community just floating around and not knowing where to go, or how to help themselves.”

“I think there are a lot of services out there, but I think it’s just that the people don’t know how to get the services.”

“I need all the information, everything that’s pertinent to my well being.”

“I believe there should be more information available to us...it should be a hot line or some place a person can call to be given information that we’ll need for a sane, healthy survival. I mean, there’s some drugs out there that interact terribly together you know.”

‘Maybe a combination of improvement of services and awareness...’

The respondents were divided as to whether or not they were satisfied with the efforts to improve health services. Half of the respondents noticed improvements in health and support services. Some were satisfied with efforts to improve these services, other said they felt it was a slow process.

“...I think it’s getting better, the system. They do best with what they have, you know, they’re still human beings, you know, they’re not perfect, they make mistakes too, you know.”

“...Yeah, I am, for the most part I am [satisfied]. I’d like to see it a little quicker, that’s all. The wheels turn slowly, we have to accept that.”

A number of the respondents were not satisfied with efforts to improve health and support services. Respondents felt such services resisted change and had misplaced priorities. They longed to see results from reform efforts.

“As far as I’m concerned they are not improving them. They are laying off workers, cutting 60 jobs for nurses, that will make things worse. The Ministry of Health wastes a lot of money. They are buying new vehicles and cutting programs. They could be spending more money on patient services but they don’t.”

“...there’s too much ‘but if, what if,’ as if it was set in stone and changes are not being made and people are so afraid to change a program. The mobile crisis unit is a perfect example.”

‘I’ll be satisfied with these efforts when I see results...I’ll be satisfied when I don’t see somebody on the bus talking to themselves, dressed in ratty old clothes, smelling like he hasn’t taken a shower in four or five days. I’ll be satisfied when they don’t medicate you to the point where you’re oblivious of what’s going on around you. I’ll be satisfied when what they say is what they do, when people aren’t lost in their own nightmares, when people are back in a functioning society, when people are accepted back into that society.’

CRISIS SERVICES

In this section respondents had an opportunity to comment on their experiences with crisis services and the quality of these services.

When respondents were asked which crisis service they used, the most frequent answer was the L.P.H. crisis department. Other services accessed during times of crisis were McKellar Hospital, St. Joseph's Hospital, Port Arthur General Hospital, Telecare Crisis and Caring Line, Shelter House, the Salvation Army Men's Hostel, 9-1-1, the Police, and the ambulance.

Respondents were generally dissatisfied with the quality of the crisis services provided.

‘Is the worse thing I’ve ever seen in my life and it’s getting worse by the day, because the staff hold prejudice...they lock you out, if you phone them they’re supposed to be 24 hour care and if you phone them in the middle of the night, they tell you to come back at 9 o’clock in the morning and it’s open or they say, ‘Wait till tomorrow...When’s your next doctor’s appointment.. Phone your social worker tomorrow.’ What if your social worker’s not around ? They don’t actually talk to you or offer emotional support; well except for one, one staff, but most of it’s run like they just don’t care and they refuse clients.”

‘There was no empathy or anything shown, you know for what I was going through.”

‘I was not satisfied with them.”

‘I was treated like shit...”

A few respondents were satisfied with the crisis services and the people providing the service.

‘Yes, I found it helpful.”

‘They are very good people...very nice.”

Some respondents said that the quality of service depended on the staff providing the service.

“...really good or really terrible, depending on who is working.”

‘There are a few people in there at least trying to survive, a few good staff members trying to survive and trying to change things, but they’re just getting trampled and they’re considered radicals

within the system because they're trying to make it better and they're fighting for the patient.”

Some suggested improvements in crisis services were staff training, more staffing, quicker response times and implementation of a mobile crisis service.

“There has to be training on how to respond, and what to do, and how to deal with them, and some sort of uniformity in application.”

“Maybe a few changes...more doctors at the same time.”

“I would like to see a crisis, crisis system that you don't have to sit there or they take one look at you and if you are fairly calm, they don't take care of you for two hours...I would like to see a faster crisis unit...a mobile crisis unit which would be, it would be excellent...”

“Mobile crisis unit...[with] a clinic attached to mobile crisis with 48-72 hour crisis beds.”

“I would like to see very much a mobile crisis unit, on call 24 hours a day...I think that would be really excellent because you could nip it in the bud before they got you to the hospital, they could defuse the situation, you know, right at home.”

Chapter 8

ONTARIO PSYCHIATRIC SURVIVORS ALLIANCE - Thunder Bay Chapter

In the O.P.S.A. – T.B.C. section we were looking for respondents' opinions about the organization, what activities they participated in, and any suggestions and/or criticisms they wished to express.

In general, respondents were in favour of the organization and its purpose.

‘It’s a good organization for survivors of the mental health system to come and do the activities we put on.’

‘As far as the concept, I think it is great... psychiatric survivors doing things for themselves.’

‘I know that they are trying to lead the way in mental health reform and that is very dear to my heart.’

We sought data on the activities and projects O.P.S.A. – T.B.C. offered, asking which ones members knew about and used. Activities most often mentioned were those dealing with social recreation, volunteering, and various types of group meetings.

‘I saw a movie there one night. I went to social rec and saw a movie...[joined] the steering committee...fundraising committee. I do want to help as much as I can if it’s behind the scenes because talking to people who accept that I’m disabled I have no problem, but talking to people in the community and having to tell them I am disabled I find really difficult.’

‘Its steering committees, resource person...conferences in Fort Frances and Toronto, been a member since ’91, like the social activities there like the Welcome Ship, made some very good friends here who know the total me which I had never been able to do before.’

‘...I’ve gone to the cruise, that was really nice. Been to a couple of parties, leadership training workshop last year, that was good.’

‘I went to a conference in Toronto two years ago. I got so much out of that! I got more out of that than everything I had read...I really enjoyed it.’

‘Well, we have a bunch of committees, we have volunteer jobs for members.’

‘I volunteer with Telefriend.’

‘I read O.P.S.A. – T.B.C.’s newsletter and I got a lot out of it. I even see the good and the bad because I read a lot and I find it’s very helpful.’

‘I like the movies that they used to have which they can’t afford anymore. I go to meetings, I go to parties they have.’

‘It seems to be trying new things all the time like video night and those dances.’

One trend that appeared from the responses was that O.P.S.A. – T.B.C. is a resource that serves to support members of the community. These comments pointed out how the organization provides members with an opportunity to get involved, to be social, and find support.

“We try to be a support towards the people that need help; the nightly phone line and all the recreation we do, parties and everything like that... basically a support for anyone who needs it, from a wife being abused to someone coming from the hospital, anything and everything. We try to better the mental health system by being involved in different communities and groups.”

‘For social skills if you want to socialize. That I have on occasion, but only when I’m up to it. I went to the party after supper because I do every now and then like to touch base with everyone.’

‘I was helping them do some filing... It gave me something to do.’

A few criticisms of O.P.S.A. – T.B.C. emerged from the interviews. Primarily they touched upon delivery of activities and lack of participation.

‘I went to a meeting one night too. It was not well organized, as I have heard from other people often happens, people were talking about their personal experiences with the mental health system rather than the topic of the meeting which was their experiences with O.P.S.A. – T.B.C. I think a lot of survivors might not understand the purpose of the meeting.’

‘They seem to be doing pretty slow progress with things like [Telefriend], I think that this could be going faster. My own criticism of O.P.S.A. – T.B.C. is that there is too much discussion and not enough action.’

“All the services that we had planned and offered went down the hole because of lack of involvement. When I first started getting involved here, I was gung ho about a self-help group which never came to pass because nobody showed up at the committee meetings or anything. They sent out surveys and everything and people wanted it, but we have to find the people who can put it in place and we haven't found anybody to do that...with the new projects, like the survival kit and stuff like that, there could be complications because of lack of involvement.”

Some comments noted that certain chapters or the province-wide organization were causing unnecessary problems which reflect on the agency as a whole.

“... problems with provincial O.P.S.A. were that they were publishing in their newsletter that people should stop taking their medications and stop going to see psychiatrists and they all want the psych hospitals burnt down and everything and some people actually do need them and for some people that's the only place they have to live. So there's opposing views and that brings conflict every once in a while. It's not that bad down here, up in Toronto it's really bad.”

“I find that some aspects of O.P.S.A. or some chapters can be, can have members that are pretty, say ah, I'm looking for a word that's militaristic type...radical is the word I'm looking for. Kinda radical like very militancy, you know, very strong and powerful and you know, they come on pretty strong. I think they want to change things too fast and they don't have patience with the hand that feeds them...I think because of that they might run into some roadblocks, you know, I don't think it's wise that we should bite the hand that feeds us, you know, because we could get cut off funding and then again, I don't think that we should compromise to the point of compromising our main prime directive, you know, I mean...the working mission statement and all that. We should stick to our guns as much as possible, but that there are some things we can, you know, we can bend, we can be flexible, you know, we don't have to be so rigid that we can't be accommodating, but working together rather than working against. I fear that some chapters of O.P.S.A. that what they're doing, they're working against the system, not with the system and it's making it hard for them.”

Respondents were asked to give suggestions for activities and projects they would like O.P.S.A. – T.B.C. to offer. Many of the responses mentioned that efforts should be made to develop and expand programs that already exist. Funding, improvement efforts, promotion and advertising

would improve quality, quantity and frequency of the organization's programs and events. Respondents also mentioned they would like to see strength, size, and participation increase.

"I think it is always a good idea to establish the services you have already before you start spreading yourself too thin and getting too many other things going."

"...it's gotta get stronger. It's gotta have more influence and more say on things...more input into what goes on ...It's still in its infancy."

"We have to get back our rights...We don't have rights in the L.P.H. And that's where O.P.S.A. – T.B.C. should come in and make sure that we're not being run over."

"I wish Telefriend would get off the ground. I think that could be a good thing."

"[O.P.S.A. – T.B.C. should get set up in] A house with two or three bedrooms, but the rest of the house would be used for office space and a common rec room in the basement."

"They are probably doing what they should be doing, but I would like it if they could have the movie ticket again, if they could afford it...I liked the idea of getting tickets and being able to go out in the community rather than sitting in a smoke-filled room with nothing but survivors."

"...anything from direct financial assistance to people by increasing their fundraising to provide direct aid to people who are in real need, have a committee or a counsellor that would suggest what aid is needed. Whether it is in recreational or fitness or something of that nature."

"...they were going to start a committee on...visiting people that are hospitalized...They tried to get some feedback from the membership...some people checked it off. I said I'd go visit people if I kinda knew them and they'd welcome me...nothing's gotten off the ground...it's just a few people doing it."

"When they have conferences, I think they should advertise it to the public...if the public wants to be informed...that would be great information for the public to hear."

COMMUNITY RESOURCES

In this section, we wanted to determine respondents' general impression of the community resources in Thunder Bay, what was being utilized, and if respondents felt improvements in community resources were necessary.

All but one respondent reported to be involved with community resources. The resources mentioned were varied and dependent on respondents' needs and interests. Examples of resources mentioned included: the Canada Games Complex, C.M.H.A., O.P.S.A. – T.B.C., theatres, the Salvation Army, libraries, churches, martial arts, line dancing classes, the Community Auditorium, sports leagues and associations, and supportive housing.

Generally speaking the respondents were satisfied with the services provided by the community resources they were accessing.

"I really like the Canada Games Complex. It's reasonably priced, they have equipment for lots of activities, pool, exercise equipment, squash courts, sauna."

"...what's available isn't bad, it can be made better, but for what's available it's not too bad."

"It has been an extremely gratifying experience. A part of me needs to put some of myself out into the community as well as utilize the resources."

Several respondents however, felt more community resources were required to meet the specific needs of survivors (i.e., mobile crisis unit, buses on holidays, counselling, education, and employment opportunities).

"I feel certain organizations could do more."

"...I see a lot of people in this town who don't seem to have a place to go. They seem to be suffering from some physical or mental disorder and they seem almost lost like throw-away people and these people need to be looked after, taken care of, accounted for."

"I don't think that there's much there for employment. It would be nice if they had a place where a person could go..."

"A lot of people have no money to do these things. Also, something like a support group out in the community like A.A. (Alcoholics Anonymous). So we would be able to go out once a

week, talk about our problems and support each other, but outside the system.”

Respondents had both positive and negative comments when speaking about the people they encountered in their use of community resources.

“I found them pretty cooperative.”

“Most people are really nice.”

“That is really mixed. Some are really into what they are doing. Some just want to make money.”

“Everybody’s different, but generally speaking, kind of on the patronizing side.”

Some respondents indicated that the people they encountered in the community perceived survivors in a certain way and that these perceptions dictated how the service providers would interact with them.

“When I was in the L.P.H., I went down to the gas station to rent a video and then I went to sign it out. The man there said to me, ‘Oh, you don’t look like one of those people.’”

“You look normal, they treat you normal. What’s difficult is there are times when I’m not normal and that’s when there’s a problem.”

SOCIAL RECREATION

In this section respondents were asked to comment on what they did in their spare time and if they utilized any recreational programs. We also wanted to determine if there were any activities survivors would like to participate in but don't, and why they are unable to engage in these activities.

The majority of respondents utilized a variety of resources and recreational activities like the Canada Games Complex, or social recreation through the C.M.H.A., O.P.S.A. – T.B.C., the L.P.H., parks, community centres, legions, etcetera. Those respondents who did not utilize formal recreation programs indicated they still enjoyed some independent form of leisure activity more geared to their needs (i.e., going for walks, going for coffee with friends, watching television). Several respondents were volunteers in various organizations.

“I don't because I have my own recreation program I do myself because I feel that there is nothing in the community that provides for my recreational needs such as camping, outdoor hikes, stuff like that.”

“I garden in the summer, I cross-country ski in the winter, I read a lot, I exercise.”

“I love to intermingle. I like going out to restaurants for dinner, lunch sometimes... going out for coffee quite a bit, that's involved in my volunteer work... go to shows, go to sporting events, hockey games, to the University Fieldhouse for volleyball games, whatever's going on there.”

“In my spare time I do a lot of things to do with volunteer work.”

“I think they're too structured and they lumps a certain target group together, which isn't necessarily healthy. A lot of recreational things I want to do, I want to do them with friends not the program, and if I lacked supports then perhaps I would use recreational programs more.”

Many respondents said they would like to participate in more recreational activities, but they were limited by financial or transportation barriers.

“You mean recreation? Oh there's lots of things I'd like to do if I had the money.”

“...because a person can only do what they can afford to do, and with the amount of money I take in every month recreation is a luxury.”

“...because I don't have a vehicle any more, they won't give me my license back. Drugs are too subduing, I can't react fast enough.”

“I'd like to get back into fishing, but that's kind of hard because I don't have any buddies that fish and I don't have a car, makes it kind of difficult.”

Some respondents mentioned they had become socially isolated because they were shy or they did not feel comfortable in large groups. Others said that illness limited their activities.

“Well, I like to do something usually besides just watching a movie or something and I am not really big on interacting with other people.”

“...I'm so self conscious of my overweight...It would have to be private because I couldn't handle anyone else around me.”

“I would like to take that Tai Chi course. I almost took it once. Depression came in and got hold of me before Tai Chi started.”

“...I like to stay home away from people.”

MUTUAL AID

This section was geared towards learning to what extent survivors depend on each other for support. We wanted to know what is helpful or not helpful, the kinds of self help groups people would like to see offered, and other kinds of supports people use.

The most commonly mentioned self help groups were the Thunder Bay Manic Depressive Association, Alcoholics Anonymous, O.P.S.A. – T.B.C., Adult Children of Alcoholics, and hospital therapy groups.

Most respondents had some experience with self help groups and over half described their experience as being positive and helpful. The most common theme that makes groups helpful is having people to talk with on a regular basis who will listen, understand, and relate to what he or she is saying. Respondents found that receiving feedback from group members helped them to find solutions to their problems. They said the self help experience made them feel like they are not alone, and this was comforting. Other respondents mentioned that they enjoyed getting out of the house.

“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, and I find that helpful when I’m understood.

“The sharing of experience. Finding out that you are not unique, finding out is almost comical. The experiences are almost the same, maybe not the same circumstances but the same kinds of thoughts and recoveries and highs and lows and everything else.”

Not all of the respondents have had positive experiences with self help. Some mentioned they felt uncomfortable because they were not listened to or understood, or they had advice imposed on them. Other respondents noted that some meetings lacked focus and structure.

“What I find not helpful is that a lot of times when you talk to people, when you start expressing some of your concerns in your life, it ends up that you end up talking about their problems.”

When inquiring about the kinds of groups people would like to see offered, the following suggestions were given.

- a) Recreational activities planned by survivors for survivors.
- b) Dual diagnosis self help groups (i.e., mental illness and drug dependency).
- c) Group to share experiences and information about the mental health system.

d) Council or amalgamation of all self help groups.

A few respondents felt that they personally had no need for self help groups.

PUBLIC AWARENESS

This section was used to determine how respondents were treated by mental health professionals, other professionals outside of the mental health field, family, friends, and the general public.

Respondents felt that generally the public's attitude towards them was of a negative nature. Respondents' experiences include being discriminated against, taken advantage of, belittled and demeaned, not accepted or understood, avoided and alienated. The respondents felt that the general public were fearful of survivors.

“When I do tell people that I was in an institution then that's when I get funny looks. Even when I cash my cheques from O.P.S.A. – T.B.C. one of the women in the bank tried ripping me off.”

“There's that stigma that's attached, my fellow workers don't really understand. They've teased and criticized me.”

“...it is the people walking down the street or people in cars. They drive by, they have ways of trying to fight you or push you around because they want to see how strong you are because you came from the L.P.H.”

“For the most part as long as I keep my mouth shut and didn't tell people what I was thinking at the time, most people treat me the same as they would anyone else, but if I tell them I'm schizophrenic a lot of people are alienated and almost frightened at times.”

Some respondents indicated that they are treated as any other member of society, or at least were not mistreated.

“I don't wear a badge, but friends, neighbours, and everybody has been sympathetic.”

“I don't go to the grocery store and say I have problems. They treat me like anyone else.”

Most respondents had negative experiences when interacting with professionals. Their comments centred around the attitudes professionals demonstrated toward survivors. These attitudes were described as being prejudicial, detached and indifferent, not treating people with respect, and behaving in condescending ways. It was also mentioned that the quality of service delivered depended on how compliant a person was.

“Other than O.P.S.A. – T.B.C., I don’t find anybody to help me out.”

“At the L.P.H. I felt the nurses were treating me as lower class.”

“Most of my experiences were in the hospital. If you’re good and do what they say, then they like you and if you do something against, then you’re the scum of the earth.”

“When they hear you have a mental illness, all of a sudden there is a very negative judgement against you.”

MENTAL HEALTH BARRIERS

This section focused on learning about the attitudes of the general public and professional people working in the system. We were interested in how these attitudes affected survivors when they try to access services, and how this impacts on people's quality of life.

Non-acceptance was common and it included stigmatization, prejudice, and stereotyping. It consisted of survivors not being listened to or understood, ignored, avoided, and treated without respect and sensitivity.

“There's prejudice if found I'm a psychiatric patient.”

“I no longer let people know I had a mental health problem because I found they were prejudicial.”

“I could hear him talking to everybody as though I wasn't present.”

“Aside from people standing back and taking a look at me after they know I've been in hospital I don't run into anything at all.”

“I've learned to be humble. I have to learn how to ask for what I need.”

Degradation and abuse were just as common and it took the form of being laughed at, humiliated and ridiculed by being the brunt of a joke or threat.

“They don't acknowledge you exist and if they do you become the brunt of a joke or a physical threat. It is much easier for the bully to pick on the one who is different than it is to pick on the one who is a part of the group.”

“I went down there and I was literally thrown out of the outpatients unit by a nurse who was yelling, screaming, abusive, and very angry and it's pretty bad when a patient goes there for service and a health care professional is in such a state that the patient has to calm them down.”

“They [hospital] strip you of your clothes and they give you pyjamas that don't fit you, you know, buttons off and rolled up; stripped of all your identity and you know they've never had that.”

“I was poorly treated so I didn't go back, feared repercussions.”

Respondents felt that public fear and misconceptions about mental health survivors is widespread in society. Respondents sensed they were viewed as being “crazy” and dangerous. They attributed such prejudices and social stigma largely to lack of education and misinformation that is reinforced by the media.

“You can’t see it, and because you can’t see it you fear it because people are afraid of things they can’t see and don’t understand.”

“The media doesn’t help things at all in portraying people with a psychiatric disability as being dangerous. That just feeds the public fear.”

“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.”

A couple of respondents indicated that attitudes and service delivery are improving.

“The doctors are less mean, you don’t have to be scared every time you see a staff member.”

“As I’ve seen, the attitudes in the hospital is not good, the attitudes of doctors in the hospital, but now that everything is moving out into the community, I find that the community, such as Alpha Court and O.P.S.A. – T.B.C., you know is getting better.”

Respondents indicated that their quality of life was negatively affected by social prejudices and stigma.

“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.”

“You got to put on a little mask and it does affect your quality of life, you’re unsure about different things like, ‘geez, do I want to go out with this lady and is she going to understand that I’m manic depressive?’ I’ve had this and it does affect your quality of life.”

“I might be depressed and if I’m depressed I can’t be around the kids because they don’t want to see a weepy father, they want to see a father, you know, who can talk and stuff like this. There have been times where it has affected my quality of life, the people don’t understand as in the legal system. Well you have to have this and it

was a battle to get it down to a reasonable access with reasonable notice. Because she pulled up this stuff the ‘oh, you’re mentally ill,’ you know, you should have chaperoned visits with the kids.”

Respondents indicated that social stigma and prejudice affected the development and maintenance of relationships.

“Up until a few years ago I would pretty well say it destroyed my life. I lost a lot of friends when I ended up in the mental health system. I moved away partly for that reason and being in the system is the most demoralizing thing that I have ever experienced, humiliating too.”

“The people that do understand a lot is the people that have been in prison, and they understand, they know what it’s like because it’s basically the same thing, basically, their rights or lack of rights.”

“I’ve had trouble in relationships because nobody wants to be involved with, you know, it involves somebody on a pension because they got that, the stigma eh, you say you’re mentally ill and right away, oh, this guy, he could be dangerous.”

Other respondents identified how having a mental illness affected their ability to find meaningful employment.

“I would still have my job if it weren’t for mental illness. When I left I was making close to \$35,000 a year. Two more weeks and I would have been a qualified conductor and my pay would have gone up to \$50,000 a year plus benefits.”

“They have affected my ability to get work, because I have a spotty kind of work history, because I have been ill and had to go into the hospital.”

Respondents’ financial limitations affected their quality of life as well.

“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.”

“I’ve had to live in a place that’s not up to my normal standards.”

A number of respondents felt that their experiences have fostered personal growth and they are better people for having gone through difficult times.

‘I’m kind of thankful in a funny kind of way for the lousy experiences I’ve had. If I hadn’t had those experiences I wouldn’t be where I am now.’

‘I’m certainly much more understanding now of people who are afflicted with mental illness, who are not perfect in the eyes of society.’

‘It has improved. I find just knowing I have the illness answered a lot of questions about previous behaviours and now I am able to put it in check.’

Chapter 14

SELF

This section was geared towards learning about the individual. We asked respondents to describe an average day in their life and what their future plans and goals are, if any.

Respondents indicated that most of their “free time” and enjoyment centred around social, leisure, and recreational activities.

“I smoke cigarettes, eat, sleep, watch television, driving, drinking coffee, and walk the dog.”

“Get up around 10 a.m., turn on the television and see what’s on, do whatever phoning I have to do, maybe borrow a car and get out. Basically if I stay home all day that’s what I do, watch television and watch my fish, hibernate.”

“I have a bath, wash my hair, read for a while or watch television, go for my walk if I can get out.”

Other daily activities were employment, school, house work, volunteer work, and personal development or interests.

“I wash clothes, clean up the house and there’s meals and dishes to think about cleaning.”

“I get up at 7 a.m. and have half an hour to an hour of prayer time.”

“Well, I’m upgrading right now and in September I will start a radio broadcasting course.”

“I have a lot of things that I’m involved with like the union and that takes one night a week minimum. Other groups that I’m involved with are service work here, so it’s probably one night a week.”

“By mid-afternoon, I have to get ready to go to work. I go to work for eight hours. This is not very strenuous work at all. I enjoy interacting with the clients.”

“I get up at around noon. I go and have something to eat, go to O.P.S.A. – T.B.C., talk to people, talk to staff for sure, I always talk to them. Then I just walk around for a few hours and go home.”

Many respondents indicated that they have future plans which include acquiring an education, finding or maintaining employment, having a relationship, and becoming financially stable.

‘In September, I’ll start a radio broadcasting course. It takes four semesters to take care of and after that put out applications to all different places and get hired somewhere.’

‘I intend to keep on doing the job I am because I have a good reputation within the organization of being able to go into different places, even when I don’t know the clients very well.’

‘Some day I’d like to have a family.’

‘I’ve worked in a lot of different fields and I’ll nail one down and get the appropriate education.’

‘Music and counselling, ideally as a career. I’d like to feel that I am contributing to something.’

‘Hopefully in two years, maybe longer, two more courses at Lakehead University and I will graduate.’

‘Find a nice job, or a job I like. I’d like to get married and have children.’

‘Very easy, getting married, settling down, having children, and being rich.’

Other plans include purchasing material items, to move or relocate, to help other people, and to work on their personal growth.

‘Personal growth is a big thing.’

‘I am being transferred to Toronto as of yesterday.’

‘I’m going to buy a suit and black cowboy boots.’

‘Buy a camera and learn to use it.’

‘I’m planning on moving, but would like to remain independent and expect to keep on helping other people.’

There were, however, several respondents who were not sure of their plans or do not have future plans.

‘I don’t see the future holding anything.’

‘I don’t seem to have any.’

‘I don’t know yet, I’m trying to figure that out.’

‘I don’t really know. I still see my doctor every six months. At this time he says to get involved with O.P.S.A. – T.B.C. and C.M.H.A.’

‘I don’t have any plans for the future, never had. I live one day at a time; half day at a time actually.’

Many respondents indicated that they have future dreams and they include having a relationship with someone, financial security, having a career or finding employment, acquiring an education, and travelling.

‘If I had a full time job making a good sum of money, I’d be thinking of buying a car and a house.’

‘I’d like financial security and to do something productive that I like and be as helpful and useful as I can.’

‘I want to get in to a treatment program as soon as possible.’

‘I dream about doing some travelling later on.’

‘Maybe some day I would like to have a family.’

‘I’d like to find a girlfriend.’

‘To have lots of money and help people who need help.’

‘I would like to get married some day.’

‘I would like to have a job and be married with a mortgage and everything. I don’t know if that is realistic, I am getting older, close to forty.’

‘More money and a lot more self esteem, a little more control over mind, things like that.’

Some respondents indicated that they have no future dreams or were not sure.

‘I don’t have any future dreams, I just want to survive the present.’

‘No dreams for the future...that’s something that the professionals don’t believe. That is, you don’t have goals and you don’t have dreams.’

‘I don’t seem to have any. I don’t think we should live on dreams, it’s not healthy.’

‘I don’t dream about the future much.’

‘None, I don’t know.’

OPEN COMMENTS

The final section of the questionnaire was used to cover any issues or concerns that may have been missed, and also to identify what people think are important issues.

People talked about an improvement in staff attitudes (i.e., understanding, humanness), training for staff (i.e., sensitization), and more accurate record keeping by hospital staff. Other responses indicated a need for expanded self help, recreation, employment, and stress management programs and services. Others wanted more opportunities for people to participate in conferences and workshops.

The following is a listing, in no particular order, of what people see as being important issues:

- a) Lakehead Psychiatric Hospital
 - i) doctors lack expertise (i.e., gender issues)
 - ii) lack of referral, gaps in coordination
 - iii) attitudes of some staff members
- b) public education regarding mental illness and stigmas
- c) lack of affordable housing
- d) more community services and activities are needed (i.e., 24 hour crisis services)
- e) social relationships (i.e., isolation, friends, and supports)
- f) holistic counselling which takes a more individualistic balanced approach to treatment and uses procedures other than solely psychiatric and medical, for example, illness prevention, education, nutrition, includes family, life skills training, etcetera
- g) development of O.P.S.A. – T.B.C. (P.A.C.E.) in areas such as:
 - i) an emergency fund for persons in need of immediate direct financial aid
 - ii) ventures directed at youth, such as a downtown drop-in centre
 - iii) advocacy for a number of issues (i.e., more social and clinical projects, identification of survivor needs and desired treatment)
 - iv) self help efforts to organize and assist groups

- v) hospital visitations and flowers
- vi) an inter-agency group to unite the different survivor and advocacy groups to increase their strength.

OVERALL SUMMARY

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 which 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 the 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 better trained staff.

Ontario Psychiatric Survivors Alliance – Thunder Bay Chapter

This section illustrated that O.P.S.A. – T.B.C. was seen by the respondents as a necessary and important resource for the community. People are making use of the activities and projects put on by the organization, but points were raised on areas that could be improved and revitalized. Suggestions were offered on how to bridge the gaps in running the various initiatives and endeavours, to expand what is already offered, to develop new ventures, and to increase participation.

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.

Mutual Aid

Mutual aid took the form of “traditional” self help groups like Alcoholics Anonymous and the Thunder Bay Manic Depressive Support Group. Survivors indicated both positive and negative experiences with these support groups. Positive experiences were more apt to occur if people felt that they were being listened to and understood. Negative experiences occurred when people felt that they were not being heard or understood. While some survivors did not see a need for self help groups for themselves, others would like to see more and different types of groups offered.

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. It 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 towards survivors. The media reinforces these public fears and attitudes. Survivors indicated that these attitudes impinge 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.

Self

Many respondents indicated social, leisure, and recreational endeavours as their primary daily activities, while others were involved with employment and education. While many survivors said that they do have plans and goals for the future, several indicated that the future holds little for them at the current time.

FOLLOW-UP PLANS: Phase Two

The follow-up plans for a subsequent phase of research intends to utilize focus groups to further investigate the issues that emerged in this report. The follow-up plans hope to clarify and better understand the findings, to discover if the findings are valid, to extract more details and specifics of each issue, and to add evidence and credibility to the findings from Phase One of P.A.C.E.'s research on mental health issues in the lives of psychiatric survivors in Thunder Bay and Northern Ontario.

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APPENDIX A INTERVIEW QUESTIONNAIRE

1. SOCIAL RECREATION

Question 1 What do you do in your spare time? (i.e., leisure, recreation, etc.)

Question 2 Do you use recreational programs?

probes: if yes: What have your experiences been?
 if no: Why haven't you used recreational programs?

Question 3 What kinds of activities would you like to participate in, but don't?

probe: if none: Why haven't you been able to do these things?

2. COMMUNITY RESOURCES

Question 1 What kinds of community resources or services do you use? (e.g., Canada Games Complex, theatres, C.M.H.A., Meals on Wheels)

probes: if have used: Were you satisfied with the community resources or services you have used?

 if haven't: Why haven't you used community resources or services?

Question 2 What kinds of services would you like to see offered in Thunder Bay?

Question 3 In your use of community services, how do you find the people you meet?

3. HOUSING

Question 1 What kinds of housing have you had in the past few years?

Question 2 Can you tell me about your housing situation? (e.g., boarding homes, approved homes, emergency shelter, subsidized housing)

probes: What kinds of problems have you had regarding housing? (e.g., waiting lists)

 What improvements have you experienced in your housing situation?
 Why?

 What have your experiences been in maintaining your housing?

If not in supportive housing, do you have any desire to get into it?

How long have you been waiting to get into supportive housing?

Question 3 What kinds of care/support are available in your housing situation?

probes: Is it adequate? Why/why not?

How have you been treated by landlords/housing authorities/
professionals?

4. FINANCIAL ASSISTANCE

Question 1 Can you tell me about your financial situation?

probes: Is your income adequate to meet your needs? Why/why not?

How does it feel to be on a limited income?

Do you want to become financially independent? If so, what would help
you to do this?

Has your financial situation affected your housing situation?

Are there any policies or stipulations in the financial assistance system
which bother you?

If you have any problems with government employees, who can you talk
to?

5. MUTUAL AID

Question 1 What have your experiences been with self-help? (e.g., self-help groups,
peer support, group therapy)

probes: Who do you talk to about your problems? (e.g., other than professionals,
such as your doctor or psychiatrist, i.e., non-formal interactions)

Do you talk to survivors, non-survivors, or both?

What do you find helpful? What do you find not helpful?

What kinds of self-help groups would you like to see offered?

6. HEALTH SERVICES

Question 1 Can you tell me about your experiences with medical and psychiatric health services?

probes: What services are you aware of?

What services do you use? What are your opinions of them?

What services would you like to see offered?

How have you found professionals' attitudes toward you?

Are you aware of efforts being made to improve the treatment of mental illness? If so, are you satisfied with these efforts?

7. HOSPITAL SERVICES

Question 1 What kind of hospital services or resources do you use? (e.g., L.P.H., McKellar, St. Joe's)

probes: if have used: Were you satisfied with the hospital resources or services you have used?

if haven't: Why haven't you used hospital resources or services?

Question 2 What kinds of hospital resources or services would you like to see offered in Thunder Bay?

Question 3 How do you find the people you have connected with in your use of hospital resources or services?

8. MENTAL HEALTH BARRIERS

Question 1 Generally speaking, can you describe to me your experiences with the various social or medical attitudes or prejudices?

Question 2 How have these experiences affected your ability to access social/medical services?

Question 3 How have your experiences as a survivor affected your well being and quality of life?

9. PUBLIC AWARENESS

Question 1 With your experience as a survivor, how have you found the general public's (e.g., store clerks, cashiers, neighbours) reaction to you as a person?

probes: if bad experience: Why is this happening (reasons)?
if good experience: Why?

Question 2 With your experience as a survivor, how have you found professionals' reactions to you as a person?

probe: if bad/good, why?

Question 3 How has your life as a survivor affected your relationships?

probe: e.g., regarding socializing, family members and friends, professionals.

10. ONTARIO PSYCHIATRIC SURVIVORS ALLIANCE – Thunder Bay Chapter

Question 1 What can you tell me about O.P.S.A. – T.B.C.?

probes: If aware of O.P.S.A. – T.B.C., have you used O.P.S.A. – T.B.C.'s services?

If have used O.P.S.A. – T.B.C. services, which services have you used?

How was your experience with O.P.S.A. – T.B.C.?

Question 2 What services would you like to see offered?

11. CRISIS SERVICES

Question 1 What can you tell us about crisis services in Thunder Bay?

Question 2 Which crisis services have you used?

probes: if have used: Did you get the kinds of services you needed?

if haven't: Why haven't you used crisis services?

12. SELF

Question 1 Could you describe a typical day in your life?

Question 2 What plans do you have for your future?

probes: Do you feel that you are or will be able to pursue your plans?

 Have you made or are you making the attempt to accomplish these plans?

Question 3 What are your dreams for the future?

probes: If you do have dreams for the future, do you feel that you will be able to accomplish your dreams or see your dreams accomplished?

 If you don't have dreams for the future, what do you feel is needed for you to dream?

13. OPEN COMMENTARY

Question 1 Of all the issues we have discussed, which ones are most important to you? Could you rank them in order of importance?

Question 2 Are there any important issues and/or concerns we haven't discussed that you would like to talk about?

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

P.A.C.E. is a community-based, incorporated, non-profit organization run 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 stigma, myths, prejudices, and misconceptions associated with mental health.

GOALS AND OBJECTIVES

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

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

To develop community partnerships for the benefit of consumers/survivors.

To validate our experiences and ensure our voice is heard.

We invite any questions or interests you may have in P.A.C.E., please call us or drop by, anyone here would be more than happy to talk or answer inquiries.

If you have any questions regarding this report or any other concerns on the efforts of the Action Research Committee, please contact Stacey Gleeson or Jim Gillespie through the P.A.C.E. office at (807) 343-4760.

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