THE LIVED EXPERIENCES OF MENTAL HEALTH CONSUMERS
AS BOARD AND COMMITTEE MEMBERS
IN THE MENTAL HEALTH FIELD
by
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B.A., University of British Columbia, 1990
A THESIS SUBMITTED IN PARTIAL FULFILMENT OF THE
REQUIREMENTS FOR THE DEGREE OF
MASTER OF ARTS
in
THE FACULTY OF GRADUATE STUDIES
(Department of Counselling Psychology)

We accept this thesis as conforming
to the required standard

THE UNIVERSITY OF BRITISH COLUMBIA
October 1995
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Date **October 5, 1995**
Abstract

The current trend in the mental health field is to involve consumers, that is, people with a mental illness who have utilized mental health services, in the development, planning, implementation, and evaluation of mental health services. This type of participation is encouraged through consumer involvement on boards and committees within the mental health field. Given the lack of awareness and understanding in this area, the purpose of this study was to explore and describe the lived experiences of consumers as board and/or committee members within the mental health field. The study employed a phenomenological paradigm to explore and describe consumer involvement. The data was comprised of 18 in-depth interviews with 9 consumers who have been involved with boards or committees within the mental health field for over one year. The data analysis of the verbatim transcripts occurred simultaneously with the data collection. The data analysis also continued into the formal analytic phase involving the extraction of meaning units and themes of experience. In the end seven major themes and four subthemes emerged and offered a portrayal of consumer involvement on boards and committees. The seven themes and four subthemes are: first, the experience of making a contribution or helping others through boards and committees; second, the experience of being responsible or accountable, subtheme, of the difficulty in being responsible, third; the experience of a power differential or inequality between consumers and non-consumers on boards and committees, subtheme of the experience of being assertive for female participants; fourth, the experience of positive outcomes such as friendship, empowerment, and increased self esteem; fifth, negative experiences as part of the process of boards and committees such as disempowerment and frustration; sixth, the experience of feeling separate or different, subtheme of the experience of feeling uncomfortable when first joining boards and committees and then gradually settling in;
seventh, the experience of stress and exhaustion, subtheme of the participants means of
coping with the experience of stress, pressure, and frustration. The participants also provided
insight into the shortage of consumers on boards and committee and suggestions for
facilitating consumer involvement. Overall, the explicated themes and subthemes illustrate the
experiences of mental health consumers on boards and committees.

Implications for consumer involvement in terms of the facilitation, evaluation, and
research are offered. General implications for the field of mental is to increase awareness and
understanding of consumers' experiences and to facilitate participation on boards and
committees.
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Acknowledgements

I would like to acknowledge and thank the people who participated in this study by sharing their stories and trusting me to tell them. I am grateful for the help of a particular participant who was involved in the pilot interview, who provided resources, and spread the news of the study among mental health agencies and consumers. I also wish to express my appreciation and respect to my committee members for their support, insight, and constructive feedback: Dr. Richard Young, thesis supervisor, Dr. J. Frankish, and Dr. Colleen Haney. I would also like to thank friends, classmates, and colleagues for their encouragement, assistance, and caring.

I am also indebted to my family, Gerry, Carol, Traci, Diana, Jennifer, and Brigitte, for their constant love and faith in me. In particular I am grateful for the teaching of my parents in the value of hard work and striving. Finally, a special thank you to my best friend Chris for his constant love, confidence, and willingness to sacrifice for my goals.
Chapter One: Introduction

Our communities, government, and mental health system are in a state of upheaval regarding the identity and needs of people with a mental illness (Carling, 1993). According to Carling, our perceptions of mentally ill persons are changing. Society is moving away from seeing people with a mental illnesses as helpless patients in exchange for a view of citizenship where the individual has rights, and participates with professionals and governmental agencies equally in directing the mental health system. The term consumer will be used to refer to people with a mental illness that have utilized services in the mental health system. The current goal of many mental health professionals and agencies, governmental offices, and consumers, is to create a climate where consumers can exercise their democratic rights and participate in the planning, delivery, implementation, and evaluation of mental health services. (Church, 1986; Health and Welfare Canada, 1988; Pape, 1992). Currently, consumer involvement has been the most active in the political arena where consumers have been recruited to sit on boards, committees, and councils for various levels of government as well as community agencies (Pape, 1988).

Despite the current push and need for consumers to participate equally in the delivery of mental health services, thereby balancing their power with that of non-consumers, there is a shortage of consumers who are willing to take on this role. Furthermore, much of the literature regarding the purpose, outcome, and facilitation of consumer involvement is from a non-consumer or mental health professional perspective. There is currently a gap in the literature from a consumer's perspective. However, if consumer involvement is to be maximized and understood, then listening to the experiences of those who have taken this role enables the discovery of the meaning and purpose it has for them. The study also sheds light on the outcomes of participation and ideas for facilitating involvement. Furthermore, it
addresses the shortage of investigations into the experiences of consumers who have been involved with boards and committees in the mental health field.

The desire to research this topic stemmed from my experience working with people who have a mental illness in a Clubhouse Model program, operated by the Canadian Mental Health Association. By working side-by-side with people with mental illnesses, I have come to appreciate what it is like to live with this disease. I have seen people strive for better health and to free themselves of the stigma associated with the label of chronic mental patient. I have been challenged to see people with mental illnesses as people first and not in terms of psychiatric symptoms and disabilities, which was difficult given my past clinical training. I have heard the voices of people with a mental illness grow stronger in demanding respect and the right to control their own destiny. This study is a reflection of their continuing journey for respect, power, and meaningful roles in our society.

**Purpose of the Study**

Given the lack of formalized investigations of the experiences of consumers who participate on boards and committees in the mental health field, the purpose of this study was to explore and describe the experiences among people with mental illnesses who have taken on participatory roles. Specifically, this study describes and uncovers the common themes experienced among the participants on boards and committees and the information shared is used to form a picture of consumer involvement. This study is a journey into the culture of board and committee membership with consumers as our guide.

Information from consumers regarding their experiences is invaluable in increasing awareness and understanding of the meaning of consumer involvement. Due to the recent emergence of consumer involvement on boards and committees it can assist bodies within the mental health system to facilitate and implement consumer participation. This understanding
can assist stakeholder groups within the mental health field in best supporting consumer involvement. In addition, the results of this study may increase awareness of this issue and provide the impetus for much needed research in the area. The study also provides validation to the lived experiences of consumers as boards and committee members.

Research Question

The research question for this study is: What are the experiences of consumers who have been involved with boards and committees within the mental health system? Specifically, what meaning can be assigned to the experiences of consumers as board and committee members?

Background to the Problem

The current trend in the field of mental health is to include consumers in the development, planning, implementation, and evaluation of mental health services by facilitating board and committee level participation. There are two significant historical factors that have contributed to the current climate in the mental health field; deinstitutionalization and the consumer movement.

Deinstitutionalization

In the 1950’s, the discovery of psychotropic medication in reducing psychiatric symptomatology sparked the age of deinstitutionalization in both Canada and the United States (Hodgins, 1987). For the first time in the history of mental institutions, there was a decrease in the patient population and people were released into the care of their communities (Foulkes, 1974). Deinstitutionalization was escalated in Canada and the U.S. by the 1960’s (Foulkes, 1974; Hodgins, 1987) and according to the Braun and Kochansky (1981) consisted
The prevention of inappropriate mental hospital admissions through the provision of community alternatives of treatment, the release to the community of all institutionalized patients who have been given adequate preparation for such a change, and the establishment and maintenance of community support systems for non-institutionalized people receiving mental health services in the community (p. 739).

According to the World Health Organization or WHO (1993), deinstitutionalization has reached all corners of the world in terms of mental health policy. However, Torrey (1988) states that the National Institute of Mental Health failed to research the effects of deinstitutionalization before instigating it. "There has probably not been such a major shift in public policy in the United States in recent decades which was initiated and carried out with such a paucity of research findings to support it. The policies behind deinstitutionalization were implemented on blind faith. In retrospect, the key word is blind" (p. 235). The trend of deinstitutionalization created a legacy of problems in providing services for people with a mental illness in the community such as inadequate provision for housing, the transfer of fiscal resources, and community support programs for people with a mental illness (Shaddish, 1984; Torrey, 1988; Trainor et al., 1992). Despite the debacle of deinstitutionalization, Torrey believes that we can learn from our mistakes and that there is growing consensus on the positive qualities of community-based programs that support people with a mental illness. The current push in the mental health field in Canada and the United States is to involve consumers in the development and evaluation of community-based
programs so that many of the problems associated with deinstitutionalization can be rectified and appropriate services developed (World Health Organization, 1993). The goal of many mental health programs is to better meet the needs of those with mental illnesses in their communities and it is believed that consumers have the right to be involved in this process as well as possess information relevant to this goal (World Health Organization, 1993).

The Consumer Movement

In the 1970's the consumer movement emerged and was led by people who had a mental illnesses and had subsequently experienced psychiatric treatment and hospitalization (Chamberlain, 1990). The consumer movement in the mental health field can be paralleled to the black, gay, and women's movement which serve to decrease the barriers these groups experience in being fully participating citizens in society. However, Carling (1993) suggested that the consumer movement is predominately in the hands of mental health professionals. Despite the lack of strength in this movement according to mental health professionals, a goal of the consumer movement has been to attain equal rights in regards to citizenship for those with mental illnesses. The consumer movement "insists that people who have been labelled 'mentally ill' speak on their own behalf and not be represented by others who claim to speak for them" (Chamberlain, 1990, p. 323). In addition, Chamberlain reports that consumer groups have also fought for participation in conferences, boards, committees and other forums from which they have previously been excluded. Despite the difficulties in achieving this, it is seen as part of the movement's aim to increase the awareness and understanding of their right to self determination. According to Leifer (1990) "the growing protests of survivors of involuntary psychiatric confinement and treatment are also a contemporary
expression of the spirit of freedom and the desire for democratic change" (p. 247).

Therefore, it appears that not only do non-consumers feel there is a need for consumer involvement, consumer groups do as well.

The legacy of problems associated with deinstitutionalization in failing to meet the needs of those with a mental illness, and the growing voices of consumers in their own movement, have created a climate today where consumers are said to be legitimate stakeholders in the mental health system. As Winram states (cited in Pape 1992b), "there is a new attitude about mental health care and much of it is a result of input from those with a mental illness" (p. 4). However, there is still a lot of ground to be travelled in this area (Trainor et al. 1992) as the mental health system is complex and like most large institutions, slow to change.

Definitions

The following list is a list of definitions of terms relevant to the research question.

Boards and Committees: A group of people who are delegated to act on or consider issues. For the purpose of this study, boards and committee will be located within the mental health system and will deal with issues relevant to this area. For sake of ease in reading, the terms boards and committees will be used interchangeably unless referring to an individual's specific affiliation. Furthermore, the term council will be represented by and included under the term boards and committees.

Consumer: Persons who have had direct experience with serious mental health problems and because of these problems, have used resources and services available to them from the field of mental health (Pape, 1988). They are also referred to as participants in terms of this study. There is an appreciation of the sensitivity of the issues surrounding the use of the term
"consumer". For ease in identifying this stakeholder group the term consumer will be used, however, it is not meant to dehumanize people who have experienced mental illness. It is recognized that first and foremost people with a mental illness are just that - people.

**Consumer Involvement or Participation**: The inclusion of users of the mental health system as part of the decision-making body which has control or power to influence the mental health system (Pape, 1988). For the purpose of this study, consumer involvement or participation will be defined in terms of consumer inclusion on boards and committees within the mental health system.

**Mental Health System**: The network of formal and informal organizations that provide services to those who have mental health issues.

**Assumptions**

In phenomenological research, the researcher makes apparent her assumptions regarding the phenomena under investigation so that the reader can appreciate and understand the filter through which the experiences were perceived. The technique used to minimize the researcher's expectations and explanations is termed "bracketing". Bracketing refers to the researcher's ability to try to maintain her beliefs and preconceptions about the topic "in abeyance while watching themes, essences, and meaning surface from the data during the process of analysing, intuiting, and describing" (Smith, 1989, p. 15).

According to Guba and Lincoln (1989), "it would be silly to suppose that the evaluator has no a priori knowledge and opinions that bear upon the evaluand and its context" (p. 212). In keeping with this idea it is important to review the researcher's assumptions regarding the topic area. The assumptions brought to the study are listed in Appendix A.
Chapter Two: Literature Review

According to Church and Reville (1989) the literature in the traditional mental health field is only beginning to address consumer involvement possibly due to the limitations of traditional research methods, journal format requirements, and an unwillingness in the academic community to learn from people's natural behaviour in utilizing the available services. However, there appear to be examples of consumer involvement on boards and committees surfacing in the literature (White, 1989). The literature regarding the emergence of consumer involvement and its purpose, outcome, and facilitation will be reviewed. Furthermore, current examples of consumer involvement as well as consumers experiences on boards and committees will be examined. The majority of literature stems from constructions held by non-consumers in regards to consumer involvement. Nonetheless, some of the literature in this field is authored by consumers, as well as by both consumers and non-consumers. The literature that appears as a joint effort between consumers and non-consumers is problematic in that it is difficult to determine the experiences of consumers alone (Church & Reville, 1989).

Emergence of Consumer Involvement in the Canadian Mental Health System

In understanding consumer involvement on boards and committees it is important to trace its origins and development in Canada. In Canada, the Canadian Mental Health Association as well as the federal and provincial governments have been the major organizations to publish information on consumer involvement on boards and committees.

Services for people with a mental illness such as mental health centres and general psychiatric hospitals began to develop in Canada in the 1930's according to Pottle (1983). In
the 1960's the Canadian Mental Health Association published a document titled, "More for the Mind" which Pottle attributes as the guiding force in the development of the delivery of mental health services in the 1960's and 1970's. In 1982, Toews and Barnes conducted a national study on the services and programs that were available to people with serious mental health problems in Canada. According to Toews and Barnes, mental health services were fragmented, exclusionary, inadequate, controlling, lacking consumer involvement, custodial, stigmatizing, and that mental health professionals held paternalistic views preventing individuals with a mental illness to make decisions regarding their lives.

In 1983 a meeting at the Canadian Mental Health Association's (CMHA) national office brought together consumer representatives to discuss critical issues for the mentally ill. Consumer participants reported that they felt CMHA was a "patronizing, do-gooder" organization that was not aware of the real needs of people with mental illnesses (Trainor & Church, 1984, p. iii). The findings of this project as well as the results of Toews and Barnes (1982) report provided the impetus to bring together mental health professionals and consumer representatives in order to achieve consensus regarding action for improving the lives of people with a mental illness. The result of this joint effort was a document titled A Framework for Support for People with Severe Mental Disabilities that would become the mandate of the CMHA in 1984 (Trainor & Church, 1984). One of the goals stated in this document was to increase the involvement and participation of consumers in the community service system. "Authentic participation by people with severe mental disabilities in matters which directly affect their lives should be a priority. Currently, much of the participation by users of services is token participation, while the real decision-making power lies in the
hands of others" (Trainor & Church, 1984, p. 25). The CMHA passed a resolution suggesting "that CMHA expand its efforts to recruit qualified persons, who have been mentally ill, as members of National Committees and for other leadership roles to assist the Association in its promotional and developmental programs" (Trainor & Church, 1984, p. 30). The question remains whether this rhetoric was ever translated into action.

In 1985, the Canadian Mental Health Association (CMHA) in conjunction with the federal department of the Secretary of State held a conference entitled "Empowerment Through Partnership" (Pape & Church, 1987). According to Pape and Church, this was the first time on a national level that consumers, family members, and mental health professionals would come face-to-face to discuss issues surrounding services for people with a mental illness. One of the recommendations from the conference’s task groups was that "community and formal organizations, including government, consult with the users of mental health services around any use which has an effect on their quality of life" (Church, 1986, p. 41). It was believed that consumers should be represented in relevant decision-making bodies such as the CMHA, hospitals, and public service sector boards. However, there was a debate in how representation would be achieved. One side believed there should be a reserved number of seats on boards for consumers, yet the opposing group believed that this policy would lead to the presence of token board members. Nonetheless, it was the agreement of this task force that consumers be involved in decision-making bodies.

In 1988, Health and Welfare Canada released a document titled Mental Health for Canadians: Striking a Balance" which suggested that one of the challenges for the mental health field was to reduce the inequities found within the system. Furthermore, the authors
proposed increasing public participation and empowering disadvantaged groups to become involved in making decisions regarding policies and systems as a possible solution to the inequity. The rationale behind this approach stems from the view that groups of people such as consumers and their families have historically had little power to affect changes, however, this could be altered by the formation of mutual aid, community development groups, and other grass roots organizations. In addition, one of the guiding principles of the document was to increase consumer participation, thereby empowering consumers to have greater control over the issues that can influence their mental health. It could also be argued that this document provided little more than politically correct statements regarding issues in the mental health field and was short on specifics in how their guiding principles could be achieved.

A survey of the literature on mental health policies across Canadian provinces further exemplifies the trend of increasing consumer participation in the mental health system. According to Macnaughton (1992), the "provincial governments are now making attempts (in written policy and in practice) to recognize officially the concerns of mental health consumers and their families, by formalizing a consultation process which includes consumer and family representation" (p. 10). Macnaughton's review of Canadian provincial mental health policies suggests that some specific action has taken place in increasing consumer involvement on boards and committees.

In 1992 a provincial Royal Commission was ordered to look at health care and its costs and as a result the British Columbian provincial government instituted the policy of New Directions (Ministry of Health & Ministry Responsible for Seniors, 1993). The health care
system in British Columbia will be reconstructed so that it consists of 20 Regional Health Boards, with some communities having community health councils as well. Furthermore, the Ministry of Health will gradually transfer control over fiscal matters to the Regional Health Boards to allow the health care system to be more specific to each community. The policy mandates that at least one third of the members on the Regional Health Boards be lay participants which could include consumers. The Regional Boards will have control over the health care dollars that come into each community therefore the roles of board members have serious implications. Nonetheless, the experiences of lay participants on these type of boards has not been addressed by research (Charles & Demaio, 1993).

Overall, consumer involvement in mental health care delivery appears to be a strong mandate of federal, provincial, and community organizations. The trend in the health care system and in specific, the mental health system is to utilize the views of all stakeholder groups in terms of decision making and planning for the future.

**Purpose of Consumer Involvement**

A host of reasons appear in the literature for consumer involvement on boards and committees. The rationales behind consumer participation suggest that it is a democratic right, enhances the decision making process by having the rich experiences of consumers presented, alters the current power differential that favours professionals, keeps professionals accountable, educates professionals, and leads to other opportunities for consumers. Furthermore, there is a debate in the literature regarding the purpose of consumer involvement. One side argues it is about the empowerment of consumers, but others assert it is utilizing consumers experiences to create a better system of care. Overall, there are a
multitude of reasons provided in the literature why consumers should be included on boards and committees.

There is some consensus in the literature regarding the purpose of involving consumers on boards and committees in the mental health field. According to the World Health Organization (1993), in the past agencies have controlled and dictated the services that are available for those with a mental illness. Consumer participation on boards and committees is based on the assumption that in democracies, people should have direct and active participation in any process that affects their lives (Canadian Mental Health Association, 1991; Pape, 1992). The World Health Organization (1993) strongly maintains, "consumers have a moral, and probably a legal, right to be directly involved in the policy and planning process for services that directly affect their lives" (p. 2). From the position of the World Health Organization, consumer involvement on boards and committees is a democratic right of citizenship. Al-Issa (1994) states that the desire to participate is a means of regaining this citizenship.

Consumers are said to enrich the process of developing, maintaining, and evaluating policies and programs that affect the lives of those with a mental illness (Canadian Mental Health Association, 1991; Health & Welfare Canada, 1988; Niles & Ross, 1992; Pape, 1988; Pape, 1992; Pape & Church, 1987; Reville & Trainor, 1989; Trainor et al., 1992; Valentine & Capponi, 1989; White, 1989; World Health Organization, 1993). According to Pape and Church (1987), consumer involvement is an "affirmation of the rich resource represented by the experience of those who have direct knowledge of mental health problems and the treatment system" (p. 9). In fact, Niles and Ross (1992) believe consumers are the
largest untapped source of information utilized when evaluating the present mental health system. Jane White (1989), a consumer who has participated on boards and committees, states that when she was in the hospital for psychiatric treatment she witnessed many ways to improve the system. White explains that when she participates on boards and committees she brings her personal knowledge of the system so that others may learn from her experiences. Similarly, Pape (1988) asserts that consumers have a unique picture of the mental health system and their experiential knowledge is useful when deciding what works and what does not. According to the World Health Organization (1993), "recognizing this fundamental fact and using consumers in a meaningful way to provide checks and balances in the design delivery and evaluation of services introduces a validity to the system that can be achieved in no other way" (p. 3). Pape and Church (1987) assert that consumers experiential knowledge of the system can help create a more humane one. In short, there appears to be consensus in the literature that consumers can positively impact the quality of services offered by the mental health system by sharing their personal experiences (Valentine & Capponi, 1988). Nonetheless, there were no examples in the literature as to how consumer involvement has helped to build a better system.

According to the literature, consumer involvement on boards and committees serves the purpose of altering the power differential between consumers and mental health workers (Church & Reville, 1989; Health & Welfare Canada, 1988). The traditional medical model has encouraged the view that mental health professionals are the experts and consumers are the passive recipients of this expertise (Cohen, 1990; Leifer, 1990). Enns (1981) asserts that the paternalistic views of the medial model deprive people with a mental illness of social
power and a political identity. According to Al-Issa (1994), the focus in the past has been on
the disabilities of people with a mental illness instead of their skills and abilities. Al-Issa
states that this stigmatization and defining self worth in terms of disabilities, create a barrier
for consumers to participate on boards and committees. Theoretically, consumer involvement
challenges this view because consumer board members are recognized as having valued
knowledge and expertise regarding the mental health system. Furthermore, consumer
involvement can create feelings of pride, autonomy, as well as the right to self determination
(Canadian Mental Health Association, 1991; Health & Welfare Canada, 1988). These
outcomes will also assist in reversing the typical power dynamics in the mental health system
as consumers will have more self confidence and esteem which may enable them to speak out
on matters which most affect their lives. According to Steve Stapleton, a consumer, "too
many people live out lives of poverty, oppression and degradation to be left to the
ministering of establishment do-gooders" (1986, p. 63). Hypothetically, consumer
involvement on boards and committees can have an impact on power differentials between
consumers and mental health professionals and may change the very nature of how people
with a mental illness are viewed in the mental health system. Nonetheless, there is no
research that has looked at whether the power differential has changed because of consumer
involvement.

In relation to this idea, it has been proposed that consumer involvement on boards and
committees will ensure that policy makers are held accountable for their decisions (Canadian
Mental Health Association, 1991; Pape, 1988). Consumers as board members are in a
position to monitor services and gauge their relevancy and productivity (Pape, 1992). As
Pape states (1992b), "participation by consumers and family members in the budget process has forced the bureaucracy to really look at choices and question why we have 'always done it this way'" (p. 4). Furthermore, when consumers are in a position of power they are less susceptible to manipulation and intimidation from others in the mental health system (Pape, 1988). In summary, the literature suggests that the involvement of consumers keeps the mental health boards and committees accountable to the people that they provide services to, but once again there is no evidence to suggest this is reality and not just theory.

A further purpose of promoting consumer involvement on boards and committees is that it can educate mental health professionals about a different side of the mental health system they usually cannot see (Canadian Mental Health Association, 1991). Reville and Trainor (1989) assert that when professionals listen to the various perspectives of the mental health system they will have a greater understanding, will find new strengths, energy, and commitment. However, Lord (1989) insists that listening to consumers tell their stories requires respect for their point of view and an appreciation that it will be a different reality from what mental health workers have experienced.

An additional purpose of consumer involvement is to prevent further injustices to other people with a mental illness (White, 1989). According to White, one of the few consumers that has written about her experiences on boards and committees, her motivation to become involved stemmed from her anger towards the mental health system. "The energy consumers bring to the table is often based on real anger with the system. 'We've been shafted!' ... Every consumer has some horror stories - from being ignored to incorrect treatment to outright abuse. The main reason consumers get involved is 'to make it better for somebody
else'" (p. 3-4). White (1989) also states that non-consumers must validate consumer's feelings of hurt and anger, thus truly listening and understanding what a consumer has to say. Overall, it appears that some consumers view their involvement on boards and committees as a vehicle for improving mental health services for other consumers as well as for themselves.

The purpose of consumer involvement is also perceived by some as a stepping stone for increasing consumer involvement in other areas such as social and economic spheres (Pape, 1988). Pape and the members from the Consumer Participation Task Group (1988) believe potential social and economic benefits for consumers such as greater connection to friends, neighbours and family, as well as the possibility of landing employment in the community, may arise due to their involvement on boards and committees. According to the Pape (1988), the goal of the Consumer Participation Task Group is to increase consumer participation in all spheres, political, social and economic.

The literature in this area suggests there is a debate on the purpose of consumer involvement which is subsequently weakening its development (Church & Reville, 1989). Some people believe the purpose of consumer involvement is to increase the quality of programs offered to consumers in the mental health field. However, others have argued that consumer involvement is about empowerment and creating an atmosphere where people with a mental illness can express their right to self determination. According to Church and Reville (1989), there are "internal philosophical disagreements, primarily about whether the agenda is about improvement of services or empowerment" (p. 24). Consequently, this debate gives support for the idea of listening to what consumers have to say regarding the
Overall, the literature suggests that the purpose of consumer involvement on boards and committees is first of all a democratic right. Furthermore, consumers can help create a better system of care by sharing their personal experiences as well as helping to alter the power differential. Consumer involvement also serves the purpose of holding non-consumers accountable for their actions and helps to educate non-consumers regarding the mental health system from a clients perspective. The literature also suggests that consumers feel their involvement helps other consumers and that participation may lead to social and economic benefits. Finally there is debate in the area as to whether consumer involvement is about improving mental health services or empowering consumers. One aspect that most of the literature on the purpose of consumer involvement shares is that it is based in theory rather than on the actual experiences of consumers.

Outcomes for Consumers

There are two main outcomes of consumer involvement on boards and committees that appear in the literature, empowerment and increase feelings of self worth. Furthermore, specific outcomes have been associated with high and low participation and will be discussed.

The current definition of empowerment in the mental health field is to give back power and control to people over their own lives or at least to facilitate the road to power and control. Given this definition, consumer involvement on boards and committees is said to be empowering for consumers (Church & Reville, 1989; Health & Welfare Canada, 1988; Lord, 1989; Pape, 1988; Trainor et al., 1992). Consumer involvement may be empowering because it provides consumers with a voice, feelings of self determination, and the power to
control and direct the process of positive change (Church & Reville, 1989; Trainor et al., 1992). However, there is debate regarding the process by which consumers are being empowered. According to Church and Reville (1989), one view of empowerment is that it gives consumers power so that they can control factors that will directly impact their lives. Yet, it is also argued that you cannot give someone power, you can only provide an atmosphere where consumers are able to embrace power, on their own terms (Church & Reville, 1989). There are many perceptions as to the nature of empowerment and the following observation by a consumer exemplifies this construct further. His remark was in response to his views on the Canadian Mental Health Association’s (CMHA) national conference in 1985 titled Empowerment through Partnership:

There was a great deal of talk at the conference about the empowerment of ex-inmates. I would like to know just exactly what this empowerment involves and how it will be accomplished. In my estimation, it is impossible to empower anyone. People must assume power on their own. By the end of the conference, it was beginning to sound like the CMHA was going to evolve some sort of ceremony where ex-inmates were anointed with the holy oil and chrism of "empowerment" and then turned loose (Stapleton, 1986, p. 62).

It appears that there is debate regarding the process of empowerment nonetheless, consumer involvement may be a source of empowerment or a vehicle for consumers to empower themselves.

Related to the construct of empowerment is the notion that consumer involvement on boards and committees will create a sense of being accepted and needed (Health & Welfare
Canada, 1988; Pape, 1988). According to Trainor et al. (1985), "participation is the key way of fulfilling the goal that people with severe mental health problems lead rich and fulfilling lives in the community, with a sense of belonging, acceptance and inclusion in community life" (cited in Pape, 1988, p. 2). Furthermore, consumer participation on boards and committees can help increase feelings of pride (Health & Welfare Canada, 1988), sense of purpose (Pape, 1988), and self esteem (Pape, 1992; Pateman, 1973). Pape (1992) also suggests that making a contribution can generate the sense of belonging, and promote overall emotional health. For example, a consumer named Mary McIlroy (1988) offered the following when she was asked to speak at the Third Canadian Congress of Rehabilitation in Quebec City in June of 1987. "Being invited to come and speak to you today is another step forward for me. It reinforces what people - and not only those who have been mentally ill - need in order to feel good about themselves and enjoy the best of what life has to offer. That is: we all want and need acceptance, support and an opportunity to contribute" (p. 29).

In addition, Al-Issa (1994) studied the rates of consumer participation in four settings in the mental health field in Canada and England. She discovered that consumer participation as defined by involvement with their rehabilitation plan, choice of residence, self-help groups, as well as control over the local service delivery, was related to certain outcomes in both high and low participators. Low participation by consumers in the above stated areas were related to not getting enough information, coercion by others, and lacking power to affect the situation. On the other hand, high participation was evident in those who felt listened to, could challenge and negotiate, who sensed equality, and gained recognition for their efforts. Therefore, different outcomes were linked with the consumer's level of participation.
Despite the paucity of research in the area, there is consensus that involvement on boards and committees may lead to empowerment and increased feelings of self worth. Furthermore low participation by consumers is linked with a lack of power whereas high participation was associated with an increased sense of personal power and control.

Barriers to Consumer Involvement

The literature points to numerous barriers to consumer involvement on boards and committees. The World Health Organization (1993) states that the "government and private service sector systems are not designed to accommodate non-professionals in the planning and delivery process" (p. 4). Furthermore, they assert that the current structure of committees facilitates the involvement of professionals. According to the World Health Organization consumers suffer from a lack of concern regarding their needs when entering boards and committees. Moreover, Church and Reville (1989) state that the knowledge in this area is couched in theory rather than in actual practice and that the lack of pragmatic knowledge has led to a slow growth in the policies that support consumer involvement. The specific barriers to participation that appear in the literature are the power differential, incongruency between the values of an organization and its practices, tokenism, representativeness, role strain, and poor communication. Further barriers include economic factors, stress, timing of meetings, lack of a board manual, under-utilization of members and their special needs. Labonte (1989, 1990) also proposes four cautions regarding the empowerment of communities, for example the community of consumers.

In the literature there have been numerous ideas regarding barriers to consumers for participating on boards and committees. A number of authors believe the power differential
between consumers and non-consumers is a barrier in itself. According to Church and Reville (1989), the progress made in involving consumers on boards and committees will be dependent on how quickly the power dynamics in the mental health system can be altered. Lord (1989) charges that the paternalistic views of the medical model which dominate the mental health field is a barrier for increasing consumer involvement. The World Health Organization (1993) states that it is difficult for consumers to be effective members given that they usually do not know anyone on the board or committee, possess different educational, economic, and motivational backgrounds. According to Church and Reville (1989), despite these factors, traditional views in the mental health field are being challenged. This includes a reevaluation of how consumers can participate within the mental health system. Therefore, it appears that the facilitation of consumer involvement is dependent on the context of the mental health system and includes altering the power differential.

Valentine and Capponi (1989) have outlined six barriers to consumer involvement. It is interesting to note that this document was written from the perspectives of a mental health professional (Valentine) and a consumer (Capponi). The collaboration between the two stakeholder groups is positive yet it is difficult to ascertain what information has stemmed from the observations or theories of Valentine, and what information is based on the actual experiences of Capponi as a board member. In fact, the article is descriptive in nature and does not indicate how they identified the barriers to consumer involvement. Nonetheless, a review of their suggested barriers is useful. According to Valentine and Capponi (1989), the first barrier to consumer involvement is an "incongruency between stated organizational
values and actual practice" (p. 9). In specific, many organizations assert that consumer involvement is a high priority, yet when examining how consumer involvement has been facilitated, there appears to be little effort to maximize the involvement of the consumer and to balance the consumer representation on committees. The second barrier cited by Valentine and Capponi is that of tokenism. Valentine and Capponi refer to tokenism in terms of under representation and/or under utilization of consumers. In terms of consumer representation, Valentine and Capponi state that "the participation and support of individual consumers should not be misconstrued or touted as broad consumer support for a committee or administrative decision" (p. 9). Consumers are not homogeneous in their needs and concerns, therefore, a board or committee should have more than one board position filled by a consumer in order to achieve better consumer representation (World Health Organization, 1993; Valentine & Capponi, 1989).

The fourth barrier to consumer involvement cited by Valentine and Capponi (1989) is that of role strain. "Role strain can be described as the tendency for roles and functions learned outside the committee to interfere with the appropriate performance of roles within the committee" (p. 10). For example, mental health professionals may adhere to a helper format in relating with consumers and experience problems in treating consumer board members as equals. Pape (1992) suggests that the inequality can be eased with informal interaction among the members such as a pot-luck dinner. Furthermore, the process of the board can be stopped at any point to examine whether or not the input from both stakeholder groups is equitable (Pape, 1992). Consumers may also experience role strain because of the clash between the sluggish pace of bureaucratic structures, with the intensity of their desire
to produce change in the mental health system (Valentine & Capponi, 1989).

A further barrier is the role of consumers on boards and committees and its lack of clarity. According to the World Health Organization (1993), there is not a clear rationale and structure for including consumers in the process of decision-making. They assert that organizations and consumers may be unsure of consumers' roles thereby making it difficult for them to be actively involved.

Poor communication can also serve as a barrier to consumer involvement according to Valentine and Capponi (1989). Most boards will be comprised of people who have different backgrounds and experiences which can make communication difficult. The jargon in the mental health field may be problematic for consumers, "the language of the meetings can be confusing as Latin, the effort to break into discussion overwhelming" (Valentine & Capponi, 1989, p. 10). Further problems with communication can be attributed to a lack of understanding about mental illness among non-consumer board members. Board members may not understand the side effects of medication and how institutionalization may have impacted on the consumer's behaviour. As a result, Valentine and Capponi assert that the chairperson of the board or committee must be aware of these factors and make attempts to promote better communication by explaining and summarizing the discussions. Written documents may also be problematic for consumers.

A further barrier cited by Valentine and Capponi (1989) and the World Health Organization (1993) is that of economic factors. For some consumers, their involvement may incur babysitting or transportation costs which can be difficult if the consumer relies on social assistance for support. White (1989) states that further financial difficulties for
consumers may arise when they are employed and paid an hourly wage. A consumer who wants to become involved on a board and committee may have to sacrifice income in order to do so. Valentine and Capponi suggest that mental health programs should address financial issues for consumers and that consumers should make their needs apparent to the Chair or administrator involved with the board or committee. Pape (1992) and Capponi (1991) assert that the financial needs for transportation, lost wages, and daycare should be covered for low income participants.

White (1989) has also suggested further barriers to consumer involvement based on her own experiences. She states that boards and committees can be emotionally draining for consumers because they draw on personal experiences. She writes, "we speak in the first person, not the academic third person. We give ourselves along with our knowledge" (p. 4). For some consumers drawing on painful experiences in the mental health field as a source of knowledge can cause them to be draining emotionally. Furthermore, Pellar (1991) suggests that veteran consumers on prestigious boards and committees are prone to burnout due to the small numbers of them being spread too thin. She also suggests that having too few consumers involved can lead to co-optation and discourages the emergence of new consumer leaders. In addition, White (1988) states that the responsibilities and roles of being a board member can be overwhelming and therefore a barrier to participation. For example, some board responsibilities require travelling to other cities. If the consumer is not accustomed to airports or hotels then these new experiences may be overpowering. Furthermore, Canadian Mental Health Association, Alberta Division (1991) as well as the World Health Organization (1993) recognize that the people who do not hold professional titles may feel
intimidated around other highly trained individuals, which may lead to discomfort in them sharing their experiences.

The Canadian Mental Health Association (1991) has listed four other barriers to participation such as the timing of meetings during the day when it may be easy for the professionals to be present but not employed consumers. Furthermore, they state that the lack of a board manual that specifies roles and responsibilities can be a barrier to participation. The other two areas mentioned by this Association is that consumers need to be made good use of as board and committee members and that any special needs they may have should be met.

Labonte (1989, 1990) has proposed four caution regarding the empowerment of communities of people. His concepts are transferable to the community of consumers. The first caution is the concept of "romanticism" or believing that everyone in the community of consumers is good. Further, the issue of "anti-professionalism" is cautioned against in which there is a lack of recognition for the facilitative role of professionals in assisting consumers. "Decentralism" recognizes that the issues within the mental health system are large and that changing policies can take a long time. The final caution is that of "self help" in that consumer participation should not permit government to withdraw their responsibility for assuring the health and welfare for consumers in general. The concepts of romanticism, anti-professionalism, decentralism, and self help could act as barriers to consumer involvement on boards and committees.

Overall, the barriers to consumer involvement are numerous and steps to alleviate the barriers could facilitate participation on boards and committees.
Facilitating Consumer Involvement

There have been some practical suggestions in the literature in supporting consumers in realizing participatory roles on boards and committees. Suggestions for facilitating consumer participation on boards and committees involved listening and respecting the views of consumers, specific recruitment methods, feeling supported when first joining, and having friends on the board. Other suggestions cited in the literature involved training and preparing consumers for board and committee work. In particular, a number of training materials for both consumers and board members have been developed.

White (1989) has insisted that the facilitation of consumer involvement requires the "investment of economic social support by the present decision-making bodies" (p. 3). For example, Lord (1989) believes that consumers must be listened to and trusted if they are to be interested in continuing their involvement on a board or committee. Capponi (1991) goes so far to say that not only listening, but respecting what consumers have to say is important. Lord states that the chairperson of the board or committee must recognize the power differential between consumers and professionals and be attentive to the needs of the consumer. Lord (1989) also suggests that mental health professionals at these meetings may need to make a role change and to free themselves of the stereotypes they hold in relation to people with a mental illness. Levine and Deneburg (1984) assert that the greater the match in the ideology among group members or individuals, the increased likelihood of a successful partnership among them. Therefore, to maximize success it is important for consumers and non-consumers to meet on equal grounds and to share similar goals and ideals.

In specifically looking at the type of supports consumers may need for facilitating their
involvement, White (1989) suggests that they need to feel encouraged, accepted, and supported when joining boards and committees. She states that consumers need to feel safe at meetings in order to be able to risk participation. White's perceptions of safety are offered in her following description:

What makes a person "safe?" My personal safety comes from knowing that I will be encouraged to manage my own life, but that if I no longer feel I can be responsible, someone else will provide protection, talk to me, listen to me, help me regain control over panic and withdrawal, assist me in making realistic decisions. A safe person accepts me, respects my opinion on decisions that affect me, and challenges me to do my best and accept the rest (White, 1989, p. 2).

In addition to feeling safe, White believes that having friends on the board will prevent consumers from feeling isolated. White (1989) states that all new board members (consumers and non-consumers) should have a mentor who can provide instruction about the policies and procedures of the board or committee. Despite White's insight into the facilitation of consumer involvement she still questions how it can be maximized.

Further supports identified in the literature are financial in nature. The World Health Organization or WHO (1993) suggests that consumers should be given money to offset costs incurred due to participation. The WHO suggest money should be provided upfront to consumers when travel and accommodation are part of board and committee work.

In reviewing the methods of recruiting consumers onto boards and committees the Canadian Mental Health Association (1991) have proposed four methods to facilitate involvement. They suggest that staff within organizations be asked to help recruit consumers.
Secondly, for staff to develop skills in consumers at a grass roots level so as to enable their participation. Furthermore, they suggest posting notices in doctors and counsellors offices, and finally, developing formal and informal linkages with consumers. In their methods of recruitment is an absence of consumers involvement in the recruitment of other consumers. This is problematic in that the professionals idea of who should represent consumers will most likely be different than the consumes idea of who they would like to represent them (Capponi, 1991). Their methods also seem to incorporate a paternalistic attitude towards consumers.

Facilitating consumer participation can also be achieved by including information on consumer involvement in the training and curriculum of people in the various professional groups. To this end mental health professionals would understand why participation is important to users as well as some of the barriers consumers may face (Al-Issa, 1994). Other authors have suggested that facilitating consumer involvement also needs to take into account the notion of back-ups, for example a consumer should get sick and be unable to attend the meetings there would be someone to fill in (Canadian Mental Health Association, 1991).

A number of authors have pointed to the need for training and preparation as part of facilitating consumer involvement. The Canadian Mental Health Association (1991) and World Health Organization state that there should be an orientation package provided. Al-Issa (1994) states that training for consumers should include information about the mental health system, policies, and legislation. She also recommends that consumers be aware of current issues in the mental health field, committee procedures, and group dynamics. Church and Capponi (1991) also called for the need to train consumers for board and committee
membership and subsequently developed a training program to specifically meet this need. The "Leadership Facilitation" package provides training in three main areas, self disclosure and communication, learning about "others" such as boards, agencies and professionals, and finally, dealing with the issues such as board structure, the minutes etc. The training utilizes role playing and homework assignments. The training is led by a consumer who participates on boards and committees. The program also provides basic guidelines for running the "Leadership Facilitation" program such as an acceptable meeting time and place. The program Capponi has helped develop is a practical and logical step in the direction of facilitation.

In addition, while participating as a board member at the Gerstein Centre in Ontario, Capponi (1991) developed a board sensitization package for the professional members she participated with. The purpose of the package was to sensitize professionals to consumers and to break down any stereotypes the professionals might possess. For example, she states that the professionals image of who should be representing consumers may not fit with reality and consumers themselves should select whom they want to represent them. She adds that professionals were never questioned as to whether they could represent the views of consumers, therefore, consumers should not be expected to live up to this standard either. The other suggestions she offers board members for facilitating partnerships with consumers are to listen and build trust, to provide good leadership, to alter their roles, as well as involving more than token amounts of consumers on the board. Capponi (1991) also shares her personal story with mental illness which is an effective tool for sensitizing the board members. The problem with Church and Capponi's (1991) Leadership Facilitation Training
Program for consumers and Capponi's (1991) Board Sensitization Package for board members lies not in their content, but in their limited circulation. These documents are excellent resources for consumer involvement on boards and committees but they do not appear in traditional journals and periodicals. The information is fragmented among organizations and only those in positions that network with other organizations appear to receive the information. The flow of information in the area is fragmented and exclusionary making its application difficult.

Lord (1989) questions whether the large amount of rhetoric regarding the facilitation of consumer involvement will lead to action. Moreover, there continues to be a shortage of consumers who are willing to embrace committee and board member roles (Pape, 1988; White, 1989). Consequently, Carling (1993) questions the degree to which the government values consumer involvement, and if so, whether they will provide training, increase the numbers of consumers involved, and provide the accommodation and support. Carling (1993) asks "do we value involvement enough to go beyond endless planning and start to systematically gather information from a large number of consumers about what they really want?" (p. 3). It is apparent that Carling believes that by listening to the experiences of consumers we may better understand and support consumer involvement.

Suggestions for facilitating consumer involvement on boards and committee include providing support and respect for those involved, a good chairperson, and a role change for professionals in letting go of stereotypes held of consumers. Consumers also need to feel welcomed when first joining boards and committees. Further ideas stem from methods of recruitment and providing training and preparation for consumers. In specific, the Leadership
Facilitation program (Church & Capponi, 1991) and Board Sensitization Package (Capponi, 1991) are two examples of training and advance preparation. Nonetheless, most of the literature is unpublished making its application hindered. Moreover, there is a shortage of consumers involved and there is a call for more support from the government in this area.

Examples of Consumer Involvement on Boards and Committees

There is some literature available regarding various boards and committees that are involving consumers in the planning and delivery of health care services. Macnaughton et al.'s (1991) review of Canada's mental health system revealed a number of provinces that utilize consumers on boards and committees. Manitoba, New Brunswick, and Alberta have incorporated consumer participation on their regional health boards which fulfil a mandate from each of their governments. For example in 1983, Regional Mental Health Councils comprised of a number of stakeholder groups were set up in Manitoba. The councils included consumers and were advisory in nature. In other parts of the country like Quebec, consumer councils have been devised to advise the hospitals regarding the services they provide. Furthermore, in British Columbia, consumers have been consulted regarding the downsizing of their largest psychiatric institution, Riverview. Although the report suggests that consumer participation is taking place on boards and committees it does not indicate to what degree they are being recognized as valid stakeholders.

In British Columbia, the World Health Organization, B.C. site, underwent restructuring to facilitate greater consumer involvement (Long, 1994). In 1993, the World Health Organization Steering Committee was staffed by mental health professionals with very little consumer input. For the consumers who had been involved with the project there was an
awareness that little had taken place to move their agenda along. Subsequently, they
overhauled the membership so that the committee would be comprised of only consumers
with the professional members serving as technical consultants. According to Long (1994),
the committee has successfully promoted and advanced consumer involvement in the mental
health system. At the very least, he suggests that the committee has dispelled myths
regarding people with a mental illness in not being productive and contributing members of
society.

In 1992, the British Columbia Ministry of Health, Mental Health Services Division
allocated 4 million dollars for “a variety of opportunities to directly involve consumers of
mental health services in delivering, managing and evaluating services in order to open up
the system so it is better attuned and responsive to their needs” (Pape 1992b, p. 2).
Furthermore, one of the stated objectives of the British Columbia Mental Health Services
Division 5 year plan was to “ensure that consumer and family representation comprise at
least 1/3 of all mental health boards, committees, and councils” (Pape, 1992b, p. 1). As a
result of the 4 million dollars allotted to consumer development, one of the programs that
emerged was the Thompson-Okanagan-Thompson (TOKO) Consumer Development Project
(Al-Issa et al., 1993). The project aim of this project was to increase awareness of consumer
involvement in the Thompson-Okanagan-Kootenay Region in British Columbia. In the
discussion papers on their project, the organizers felt that they had scared some of the
consumers entering board and committee work by not providing advance training, thus, the
need for an orientation manual emerged (Al-Issa et al., 1993). A handbook was developed
and the topics covered in the book were: an overview of the mental health system, functions
of the mental health centre staff, programs of the mental health services, a typical structure of a society, what is a board, what is a committee, how board and committee meetings work, helpful things to remember (e.g. have support and do not take too much on), a glossary of terms, and an appendix with useful items such as sample agenda meeting (Al-Issa et al., 1993b). A further development was a board workshop for consumers designed to elicit the interest of consumers in becoming involved, as well as increasing their skills and confidence (Al-Issa et al., 1993c). Across Canada there appear to be examples of consumer involvement on boards and committees emerging on the literature, however, "experience has also shown that even the best intended plans to include consumers in the decision making process are hard to realize" (World Health Organization, 1993, p. 4).

Consumers Experiences on Boards and Committees

The few consumers that have published material in the area of consumer involvement provide an initial picture of this experience. A publication by Pape (1988) on the efforts of the Consumer Participation Task Group, sponsored by the Canadian Mental Health Association, included written reports by consumers as to their involvement with this committee. One of the experiences for the Chairperson of this group who was a consumer, was the realization that CMHA had more to offer than he had originally experienced. "Most of my efforts in the mental patient's rights movement were fuelled by anger at the abuses of the mental health system and 'do-nothing' organizations like CMHA. With a smug sense of superiority I believed that anyone involved in such systems was worthy of little trust or respect" (Beamish, 1988, p. 40). However, as a result of his experience with the Consumer Participation Task Group which was sponsored by CMHA, he was able to alter his view of
the organization and its efforts in the field:

I am finally able to acknowledge that concerned, caring people are where you find them, be that within the CMHA, the mental health system, a self-help group, government or the community at large. And, I freely admit that the process toward greater influence within CMHA which is being made by consumers of psychiatric services could not have begun had not the organization first opened its doors to us and lent an enabling hand (Beamish, 1988, p. 40).

A further view offered by another consumer in the Consumer Participation Task Force illuminates a different experience of involvement with this group. "Our abilities to manage and our need for help varies from time to time. But within the Mental Health Association, I have found people who understand, challenges to keep growing, and opportunities to share what I am learning. It doesn’t matter whether I'm sick or well - I belong" (White, 1988, p. 46).

In another publication, White (1989) elaborated on her experiences as a board member. White (1989) states that as a new board member she felt uneasy, uncomfortable, and lacked confidence in her abilities. She also believes that other board members were also tense around her at first. Another consumer echoed this view in Capponi’s report (1991), “I do sit on boards, and I have a lot of trouble speaking there. Every time I open my mouth I feel like I’m putting my foot in it. And I find it very hard to understand the jargon they use. When I say that they look at me like I’m a dummy. I don’t think I’m a dummy” (p. 16). Jane White also mentions that her role of board member included her bearing the responsibility for educating other board members about mental illness. For White this responsibility placed
additional pressure on her and was more of a burden than anything else. She also reports that she felt overloaded with boards and committees because of the problems in contacting and involving other consumers in the same role. "I could hardly believe that vocal consumers were so hard to find. When we’re in hospital together, we see lots of ways to improve the system, or at least ways that it has failed us" (p. 2). Garry Long (cited in Carling, 1993) echoing White’s view, states that consumers who are currently involved are stretched thin by too many committees and boards, with little preparation and support to further their problems.

Despite the apparent lack of information on consumer’s experiences with boards and committees, the few examples illuminate the range of experiences of consumers. In order to arrive at a better understanding of their experiences, more investigation in this area is necessary.

Summary

The literature regarding the emergence of consumers involvement on boards and committees was traced within Canada to the Canadian government and Canadian Mental Health Association, both having published material about the work they have done in this area. Furthermore, the literature offered many perceptions on the purpose, outcomes, barriers, and suggestions for facilitating consumer involvement. The purpose of the involvement ranged from being a democratic right to empowerment, to utilizing consumers’ experiential knowledge to create a better mental health system. Moreover, outcomes cited were empowerment and increased self esteem. Barriers to participation were numerous including hypocrisy in organizations, tokenism, and poor communication. Suggestions for
facilitating consumer involvement ranged from providing support and respect, to that of advanced training and preparation before entering boards and committees. Some examples of consumer involvement on boards and committees across Canada was provided as well as experiences of consumers who have been involved.

Three main problems exist regarding the literature in this area, first, that there is a lack of research into board and committee participation for consumers. Secondly, a lot of the existing literature is based in theory rather than in actual practice and displayed outcomes for consumers. Finally, the majority of the useful and practical materials in the area of consumer involvement are unpublished manuscripts making widespread awareness and application difficult. Overall, the literature in the area suggests that research that looks at the experiences of consumers on boards and committees is needed and valued information.

Reville and Trainor's (1989) statement describing how consumer's feel in relation to the mental health system, can be paralleled to the body of literature on consumer involvement. "They [consumers] are confused and puzzled. All the talk is about them but no one is talking to them" (Reville & Trainor, 1989, p. 1). The literature suggests it is time to stop talking about consumer involvement and to start listening to consumers who have been involved.
Chapter Three: Methodology

A phenomenological paradigm was utilized as the methodological approach of this study. According to Giorgi (1970), phenomenology concerns itself with the study of phenomena as experienced and lived by people. Since phenomenological research focuses on the lived experiences of participants, it was an appropriate methodology for exploring and describing the meaning of consumers' experiences as mental health board and/or committee members. A pilot interview with a consumer who participates on numerous mental health boards and committees provided additional evidence for utilizing a phenomenological method in exploring consumer's experiences. The pilot interview provided a rich and descriptive account of consumer involvement and its meaning which could be broken into themes. Furthermore, the pilot interview brought to light the researcher's perceptions and assumptions regarding consumer participation on boards and committees, which were subsequently recorded. Seeing the researcher is the tool for data collection, the realization of one's presuppositions and subsequent understanding of them is an integral element of phenomenological research designs.

A discussion of the methodology includes information on the selection of participants, ethical considerations, characteristics of the participants, the process of data collection, the analysis of data, and the trustworthiness of findings.

Selection of the Participants

In keeping with a phenomenological tradition, purposeful sampling was utilized in the selection of participants. Key informants or active consumers in the field were originally going to be used in order to gain a rich and descriptive account of consumer involvement on
boards and committees. However, this was not necessary as the individual involved with the pilot interview was able to spread the word of the study and recruit other consumers quickly. Additional participants were recruited by networking with colleagues, consumers, and mental health agencies. The sampling continued until there was repetition in the data of the themes of consumer involvement and when the number of participants reached 9.

Criteria for the Selection of Participants

The participants in this study had a history of mental illness and had received services from the mental health system. They acted as board or committee members for at least a one year period and the board or committee they participated on dealt with issues in the mental health field. The period of one year was deemed by the researcher to be a sufficient amount of time over which the participants could discuss their experiences on boards and committees. The participants were mentally stable so as to ensure that the information would be reality based. The participants were also able to clearly discuss their experiences in English which was imperative given the method of analysing the data according to meaning. In addition, the participant who was involved with the pilot study was also included as a participant as they met the above stated criteria.

Procedure for Participant Recruitment

The consumer who volunteered for the pilot study is active in the area of participation on boards and committees. They became a key informant and helped recruit others. By networking with other agencies this individual advertised the study and consumers who were interested then contacted me by phone.

Additional recruitment of the participants was accomplished by placing advertisements in
consumer and mental health agencies throughout the Lower Mainland in British Columbia (see Appendix B). The advertisement indicated that consumers who were interested in participating in this study should contact the researcher by telephone. At this point, a letter explaining the nature of the research was mailed to each prospective participant (see Appendix C). Approximately 10 days later upon receipt of this information, the participants were contacted to confirm their involvement in the study and to arrange a date for their first interview. The initial part of each interview was used to address any questions the participants may have had. Each participant was asked to read and sign a consent form regarding their participation in the study.

**Ethical Considerations**

Before initiating the recruitment of participants and the collection of data the researcher received approval from the University of British Columbia’s ethics committee for research involving human subjects.

The rights of the participants were protected by providing them with accurate information on the research question, the purpose of the study, how the data will be collected and analysed, and confidentiality. Each participant was assured of their privacy in relation to the material they shared with the researcher. Participants were informed that they would be quoted verbatim in the results section of the study. Furthermore, the information provided in the consent form was discussed verbally and a written copy was given to each participant (see Appendix E). The consent form clearly indicated that participants had the right to refuse involvement, to answer any questions, and the right to withdraw from the study at any point in time.
Characteristics of the Participants

The nine participants who volunteered for the study were comprised of five women and four men. Their age range at the time of the study was 19 to 51 years. Four of the participants resided in the Vancouver region, four in the Fraser region, and one from the Kootenay / Rocky Mountain region (see Appendix F). Two participants were involved in boards and committees outside their geographic region, however, the majority of participants sat on committees and boards within their region. All of the participants had been involved with boards and committees for longer than a one-year period. Five participants had under five years experience as board or committee members in the mental health field. The remaining four participants had a range of 6 to 11 years experience on boards and committees. At the time of the study all participants were currently participating in at least one board or committee.

The number of committees the participants were involved with ranged from 1 to over 20. Across the participants, the range of boards and committees were as follows: mental health organizations and associations, agencies, provincial, regional, interministerial, government advisory committees, hospital, as well as strictly consumer boards. All participants shared the experience of being one of the first consumer representatives on a board or committee. At the time of the study, four participants were employed in the mental health field. The remaining five participants were not employed but did receive honoraria for their board and committee work. Eight participants had post-secondary education, with three of them holding a professional degree or diploma. The remaining participant was currently working on their grade 12 diploma. Three participants were currently married, three participants were
divorced or had been married in the past, and three of the participants had children.

It appears that the sample group shared many similarities such as education level and being the first consumer representative on specific boards and committees. Nonetheless, the range in years involved on boards and committees, number of committees and boards, as well as type of board varied greatly among the participants. Furthermore, the format of the interviews with other participants did not differ from that of the pilot interview.

Data Collection

Giorgi (1975) asserts that meaning making in phenomenological research involves assessing the world of the participant through the verbal descriptions they offer of their experiences. "For phenomenology to understand the phenomena of the world as they are experienced by man it is far better to understand man’s lived relations with the world rather than the stream of experiences that appear to a disinterested spectator of that world" (Giorgi, 1970, p. 86). Participant’s experiences were gathered utilizing two individual in-depth unstructured interviews. The initial interview explored and uncovered the experiences of consumers as mental health board and committee members. These lasted 60 to 120 minutes which was congruent with the pilot study. They took place in a private, convenient, comfortable location for both the researcher and participant, usually either home of those involved. The researcher ensured that the interview conditions facilitated an open and serious atmosphere so that the participants felt secure in sharing their experiences with the researcher. Each participant was asked to describe and elaborate on their experiences as a board or committee member. Participants were also encouraged to discuss what meaning these events and experiences played in their life. The interviewer put forward the research...
question to the participants at the onset of the interview in order to allow for a spontaneous discussion of their experiences. Trigger questions and probes were then used to clarify and understand the meaning of participants' experiences (see Appendix G).

The second interview was used to clarify and validate the data analysis by the researcher. This was achieved by presenting each participant with a preliminary thematic analysis of their first interview. Each participant was asked to describe any distortions or exaggerations in the analysis, clarify any issues, and indicate whether the themes accurately portrayed their experiences as a board or committee member. For the most part, feedback from the participants indicated that the researcher's portrayal was an accurate reflection. Nonetheless, where corrections were necessary the appropriate changes were made in the coding.

One of the participants requested that a small piece of information she had revealed in the first interview be left out of the data. The rationale behind this was she had been sworn to confidentiality over this material and had subsequently broken this by telling the interviewer about it. Due to the distress and great concern of the individual in breaking her confidentiality it was agreed after consultation with the chair of the thesis committee, Dr. Young, that the information be removed from the transcription and the tapes erased directly after. The participant was pleased with the decision and fully participated in the follow-up interview.

Data Analysis

Phenomenology aims to deepen the understanding of a phenomenon by gathering real life constructions of participants and weaving them into a picture. The picture created through the analysis of the data will be sensitive to the participants' interpretations of their experiences.
However, the meaning of these experiences are readily available to the researcher through the descriptions provided (Giorgi, 1986). The descriptions provided by participants were audio taped and transcribed verbatim following each interview. The process involving the identification of themes began with each transcription due to the emergent design of this approach. Nonetheless, a series of steps was applied in the explication of themes and categories as outlined in Giorgi (1975). The steps involved in Giorgi’s analysis of data are as follows:

1. The researcher reads the entire description straight through to get some sense of the whole. 2. The researcher reads the same description more slowly and delineates each time that a transition in meaning is perceived ... [and] obtains a series of meaning units or constituents. 3. The researcher then eliminates redundancies, but otherwise keeps all units. He [she] then clarifies or elaborates the meaning of the constituent by relating them to each other and to the sense of the whole. 4. The researcher reflects on the given constituents, still expressed in the concrete language of the subject, and transforms the meaning of each unit ... into the language of psychological science...

5. The researcher then synthesizes and integrates the insights achieved into a description. (pp. 74-75)

This procedure involved drawing units of meaning from the participants’ statements and experiences. The meaning units were subsequently categorized in groups that contained similar essences. The research question guided the division of the meaning units and asked what each sentence revealed about the experience of board and committee membership. The resulting categories and themes yielded a portrayal of consumer involvement on boards and
committees.

The Ethnograph computer software for qualitative research was used to facilitate the data analysis. Each interview was entered into the program for coding and categorization. Certain portions of the coded interviews were retrieved and printed for use in the report.

**Trustworthiness: Credibility, Transferability, and Dependability**

The trustworthiness of qualitative research can be evaluated in terms of its credibility, transferability, and dependability. According to Krefting (1991), credibility in qualitative research can be achieved when the researcher has described and unveiled the lived experiences of the participants. Guba and Lincoln (1989) state that credibility involves matching the constructions offered by participants to the created reality of the researcher. In essence, the participants should be able to recognize the researcher’s description and interpretation of their experience. According to Guba and Lincoln (1989), one method for achieving credibility involves checking with participants regarding the validity of the researcher’s construction of their reality. Participants in the study had an opportunity to provide feedback on the preliminary analysis of their first interview, thereby correcting for distortions and exaggerations, expanding descriptions, and validating the data. These procedures enable results that are credible and that accurately portray the multiple realities of the participants.

A further issue involved in establishing credibility in qualitative research involves addressing the constructions of the researcher towards the topic area. The researcher of this study was once a mental health worker and possesses views towards consumer involvement on boards and committees. According to Krefting (1981), one can employ reflexivity in order
to assess the influence of the researcher's background and constructions in the research study. For instance, prior to the onset of data collection the researcher made note of personal assumptions and expected themes from the research (see Appendix A). Furthermore, the researcher kept a field journal during the research process, specifically in the data collection phases, in order to increase awareness of any biases taking place. Once aware of any biases, the researcher took steps to alter the manner of data collection and analysis. These measures helped ensure greater credibility of the data.

The credibility of the study was also enhanced utilizing a peer examination of the research findings (Krefting, 1981). A colleague was asked to review the transcribed material from a randomly chosen participant including both interviews and extracted themes, to ensure that the researcher had accurately reflected the experiences of the participants. The second reader reported that they could understand the coding of the researcher almost 100% of the time. This increases the credibility of the findings as the additional reader could see the rationale in the coding scheme thereby assuring of little bias intervention by the researcher.

Guba and Lincoln (1989) assert that qualitative research is deemed transferable when the researcher has provided enough descriptive data so that inferences may be formed that can be used as a source of comparison to the reader's situation. The results section of this study provide a rich account of consumer involvement through an abundance of direct quotes from consumers regarding their experiences. Under these circumstances, the research study has greater applicability (Krefting, 1991) or transferability (Guba & Lincoln, 1989).

According to Guba and Lincoln (1989), the dependability of qualitative research relies on its ability to include sources of variability in the analysis and discussion of the data. The
variability in the data may be a result of the range of participant's responses from atypical to average. However, as expected, the experiences across participants contained commonalities that were organized according to themes. On the whole, the data analysis and discussion of the results did not exclude experiences based on their character, in contrast, a range of experiences are discussed thereby making the results of the study more dependable.

Limitations

The limitations of this research are rooted in the phenomenological approach itself. This study was exploratory in nature and utilized purposeful selection thereby preventing the generalization of the findings to the larger consumer population. The experiences of the participants illustrate participation on boards and committees and are not an all encompassing description. Given the number of participants the generalizability of the study is not suggested. Nonetheless, the researcher increased the generalizability or transferability of the findings by providing a thick and descriptive account of consumer involvement. This allows the reader to form inferences that may be applicable to their own situation (Guba & Lincoln, 1989).

In qualitative studies the researcher is the tool for collecting and analyzing the data. The filter through which the researcher views the data shapes the order and appearance of the findings. The preconceptions of the researcher were held in abeyance or made apparent through keeping a journal, a peer review, and a list of assumptions held by the researcher prior to the onset of the study (Appendix A). In addition, the personal meanings of the study are discussed in Chapter Five to illustrate the researcher's filter throughout the study. The biases of the researcher are made apparent in this study so as to allow the reader to discern
its impact on the collection and analysis of the research material.
Chapter Four: The Results

The purpose of this chapter is to describe the experiences of consumers as board and committee members within the mental health field. Excerpts from the participants are presented in terms of common themes. There were a number of notable similarities in how the participants experienced involvement on boards and committees. The accounts yielded a rich and descriptive image of their experiences on boards and committees.

Before discussing each of the common themes, a brief summary of the salient experiences of the individual participants is provided. The descriptions help familiarize the reader with the story that is unique to each participant. Each summary reviews the participant's status on boards and committees, the story of how the person became involved in this area, what they would miss most if they could not participate on boards and committees, and a summary of their experiences. Due to the fairly recent emergence of consumers on boards and committees and their relatively few numbers, the descriptive information on the participants is minimal so as to prevent their identification. Furthermore, the participants have been given fictional names which are used consistently throughout this paper.

Description of the Participants

Jim

Jim sits on several mental health advisory committees and is enjoying the challenge. When asked to tell the story of how he became involved with boards and committees, Jim offered a description of his troubled upbringing and family life. At one point in his youth Jim remembers having very low self esteem, "I was a couch potato, like laid at home for three
50

years and didn’t go anywhere because of an [injury], and stayed at home.... didn’t have enough [of] what they call self esteem". Jim mentioned that he has been on medication for most of his life and has a history of suicide attempts. During one of Jim’s hospital stays for a suicide attempt he remembers being upset at the treatment offered to him:

I was in a room for like 3 to 6 hours that night, and the nurse said, “Oh yeah, do you want to talk,” and I said, “Oh yeah, sure.” Um, then she says, “I can’t talk right now but I’ll come back and see you,” so an hour and a half later she comes back and I said, I asked her, “Are you ready to talk yet?” and she says, “no, no, I’m just really busy you know,” she says, “Take a pill you know.”

Jim went on to add that he was also promised bi-weekly meetings with a psychiatrist that never materialized which increased his distrust and anger at the mental health system. During a later stay at a treatment facility, Jim was asked to represent his peers on a consumer committee that brought ideas and concerns to the management. Jim remembers enjoying this role, "it brought up my feeling, oh, okay, I’m being useful here right". Once Jim completed his treatment at this facility he was connected with outside mental health agencies where he was recruited to participate on another mental health committee. At the time of the study Jim’s list of committees had grown and he seemed to be enjoying the challenge.

Jim believes he is in a position to affect change that will benefit other consumers, rather than being a passive recipient of mental health services. When asked Jim what he would miss most about participating on boards and committees he said, "power". Jim states that he feels powerful when he brings up issues and when people respond to them. Jim feels empowered by the fact that his experiences and opinions can be used to affect change.
When asked to summarize his experiences on boards and committees Jim quoted a song he had once heard, "Everybody wants to know what I am, what I am ... I am an English man, I am African, I am Indian, I am human." When reflecting upon this song with Jim, the essence of his statement became clearer. Boards and committees bring different people together for the purpose of helping others. He sees himself as "getting back to basics", and focusing on human needs.

Mark

Mark participates on numerous boards and committees comprised of strictly consumers, advisory councils, mental health committees, and agency boards. During the course of the two interviews Mark was indecisive as to whether he would continue participating on the various boards and committees. When asked the story of how he became involved on boards and committees, Mark explained he was involved with a mental health agency that was recruiting board members. One of the staff at the agency put his name forward to the upcoming annual general meeting as an interested board member, along with other consumers. Mark stated that he was the only consumer to show up at the meeting therefore he was elected to the board.

At the time of the interview, Mark was participating on numerous committees and attributed this to his reputation as someone who will speak up about issues and has the respect of others in the field. He has been recruited to a number of committees because of his reputation. "It was only after doing a few board and committee things that people hear about your performance, it's like reputation ... and get known to prove yourself, just like a mechanic or, you can have all this training but if you haven't practically applied your
training then your, then you don’t have any experience right.” The networking and word-of-mouth of Mark’s board work has opened up many new opportunities to be involved in other boards and committees.

It was the researcher’s impression that Mark had many goals and ideas as to how the mental health system could be improved and how to offer better treatment to consumers. Yet, in the first interview Mark reported feeling overwhelmed and burnt out due to his board and committee work. Mark was confused and debated whether or not it was worth the sacrifice and anguish to be involved anymore. In the follow-up interview Mark said he had decided he would take a leave of absence from board and committee work in order to decide what he wanted to do for the long term. When Mark was asked what he would miss most if he left his board and committee work which was especially relevant at this point in time, he mentioned two things; “meeting new people, watching the movement grow and change”. Mark stated that the friends he had gained through his participation was one of the things he would miss most. At the last contact with the participant he had decided to stay involved but realized that he needed to look at the ways he dealt with the stress. It appears that Mark’s quest for change in the mental health system through board and committee work has resulted in a great deal of frustration and burnout. Nonetheless, there have been many positive consequences for him which led to his ambivalence about continuing to participate on boards and committees.

In summarizing his experiences on boards and committees, Mark said they were, “fulfilling frustration …. I mean sometimes it’s fulfilling, it’s always frustrating and not too often it’s demeaning”. At the time of the interviews, Mark’s struggle was in determining
which side was stronger, the fulfilment side or the frustration part of board and committee work. For Mark, the fulfilment was diminished by the frustration and this is wearing thin on his motivation for participation.

Mary participates on a mental health board and two committees yet she does not usually enjoy the work that is involved. When Mary was asked the story of how she became involved she said, "before I got my job I didn't even know there were these committees." The only reason that she is involved is due to her job as a mental health worker although she states that she tries to have minimal contact with the board and committees. Mary believes that her energies could be put into other projects that would yield better results, however, her position in the mental health field dictates that she participate.

Mary's view towards boards and committees is mostly negative. She said that when she first started she hoped for change and for people to truly listen, however, this has not been her experience. Mary also talked a lot about her distrust of the system and the abuse of power in the traditional mental health field. It was the impression of the researcher that Mary does not view consumer participation on boards and committees as a genuine means to make real changes in the way services are delivered and operated. When I asked Mary what she would miss most about board and committee work she laughed sarcastically and said there was nothing she would miss. She reported that it would be a good thing if she didn't have to be involved any longer:

No I wouldn't miss, like I say I don't think any changes are going to come out of them, I don't feel that the people that profess this new liberal attitude of
listening to the consumer, I don’t believe them when they say that, and maybe that’s mispainting them over with the same brush, the way they’ve painted consumers with the same brush, but if I saw any kind of opening, any kind of leeway, any kind of change, you know, at all, from them, I mean I would be in there like a dirty shirt.

Mary’s view of board and committee work was unique among the participants, however, many of her experiences were also shared by other participants.

When I asked Mary to summarize her experiences on boards and committees she offered the following account:

My experiences have confirmed what I thought was all, I mean I went in there with [the] expectation of [what] has come true, and it’s not because like I think that I’m able, I think I that I’m capable of seeing if there were to be any change you know ... and really thinking that people were really interested right really, well I really did have that expectation, and then to be sort of disillusioned, and now it’s just like you know it’s part of [the] game.

For Mary, the involvement on boards and committees has been disappointing in that she doesn’t see any real changes taking place, it is just a token practice due to a mandate from the government.

Julie participates on a mental health board and committee. Julie became interested in board and committee work as a result of some volunteer work she was involved in a few years ago. Her volunteer work included providing services for other consumers which was
Initially motivated by her own experiences with mental illness. During her volunteer work, she heard that a mental health agency was recruiting for board members. She went to a meeting for interested parties and found herself quickly appointed to the board. Julie states that the agency was trying to recruit consumer board members at the time and there were few consumers who had shown interest in participating. Julie believes this was the reason behind her quick appointment to the board.

It was apparent in the interviews that Julie enjoys the board work for the challenge it offers as well as the ability to help consumers. Nonetheless, Julie was straightforward as she spoke about the downside of board work, of the frustration and aggravation of trying to achieve tangible results. Furthermore, it was the researcher's impression that she is still trying to define her role on the board and committee she currently participates on. When Julie was asked what she would miss most about board and committee work, she discussed the intellectual challenge that it offers her:

I'd miss the argument, I like the argument and I like challenging people, and it is a place where you know we can get into some pretty good discussions and it's, everybody's friends when it's all over. I like that debating society sort of aspect of it although there are times when I'm too tired to deal with it but I find it quite enjoyable and I'm able to deal with it.

It appears that Julie enjoys her board and committee work however there are times when it is difficult and draining.

In summarizing her years of experience with the board and committee she participates on, Julie offered the following account of its impact on her personal struggle with mental illness:
I would say that it's been, a very interesting sort of journey for me in exploring my own relationship to this illness that I have, I guess, a lot of what I react to I think are my own insecurities and feelings about it you know, I think I do to a certain extent project things onto other people's own fears and insecurities and things like that, but at the same time it's by interacting with those people and challenging these things that I get behind it whether I get beyond it myself or I change other people's points of view, help them get beyond it, there is a change process.

One of the results for Julie so far has been her acceptance of her illness and increased self esteem.

Nancy participates on advisory committees, consumer and government councils, and agency boards. She offered a detailed account of her background leading up to her involvement on boards and committees. When she was first ill she became involved with volunteer work in order to prove she wasn't "lazy". She stated she eventually became burnt out from her volunteer work and left. She subsequently became sick again and was referred to a psychologist. From there she eventually became connected with a doctor at her local mental health centre. She remembers seeing an advertisement for board members for a local mental health agency and was interested. Nancy said that her primary concern was that people didn’t understand the difference between a mental handicap and mental illness. Her goal was to assist in the delivery of services that would best meet the needs of those with a mental illness, not a mental handicap. After responding to the advertisement Nancy was
elected to this particular agency board and has remained there to this date. She stated that
the other boards and committees she is involved in came about in a number of ways, she was
invited to participate on a few, and there were others where she invited herself. Nancy stated
that she has a phobia regarding paid employment and board/committee work allows her to
gain some of the benefits associated with working, without the "trappings of money" and a
"lack of freedom that's so threatening."

It was apparent throughout the interviews that Nancy is passionate about supporting and
protecting other consumers. Furthermore, Nancy's participation on boards and committees is
an integral part of her self esteem. When Nancy was asked what she would miss most about
board and committee work if she couldn't participate any longer, she offered the following.
"Purpose, meaning, identity, everything would be missing, I would have to find something
else because there's no me, so I would have to have something else because there's no me,
there's only what I do is what I am." It is clear that board and committee work plays a
central role in Nancy's life.

In summarizing her many years of experience on boards and committees, Nancy
provided an interesting analogy:

What comes to mind [someone] described once as a dragon bunny
and that's it, she's soft and wonderful but she can be a real dragon and I think
that's the same way, that this whole thing participation is has those two
components to it and I like to think I'm bit dragon bunny too but I think in this
system the involvement has those two components, it's extremely rewarding
but the rewards are very few and far between, so I don't know, I don't want to
belie everything I’ve said by saying that it can be ever so rewarding, but the
rewards that you get from it are not necessarily those bestowed upon you by
others but the internal satisfaction that you get even from just hanging in an
making it to another meeting sometime.

It appears that Nancy’s experience on boards and committees are similar to other participants
in that it has been filled with fulfilment as well as frustration. On the whole, Nancy seemed
to find her board work fulfilling, yet there were barriers and frustrations she had overcome
in the process and that she continued to deal with at the time of the interviews.

Gerry

Gerry participates on a mental health board and is enjoying the challenge. When Gerry
was asked how he became involved he explained that it started when he was very ill and had
to be hospitalized. One of the psychiatric nurses at the hospital suggested that he get involved
with a volunteer program at the local mental health agency. He believes that the nurse saw
him as leading a "very reclusive lifestyle" and thought he would benefit from contact with
other people. He became involved with the agency and ended up participating on a committee
that was aimed at getting feedback from consumers regarding the agency. Gerry attended the
committee on a number of occasions and was fairly vocal about his views. A few of the
board members from the agency were also at these committee meetings and said that they
thought he could make a contribution at board level if he were interested. From there he met
with some of the board members and told them about himself. He attended a nominating
session, was asked questions, and was then asked to serve to which he replied yes.

Gerry’s role on the board has helped increase his self esteem and belief that he can use
his skills and abilities for the benefit of others. He appears to be very positive about his experiences on boards and committees. When asked what he would miss most about his board work he offered the following:

The feeling of participation and working to benefit others, I think I would miss that, you know in my previous job, I felt in the beginning ... this is a job where I'm going to be able to benefit a lot of people and I became very disillusioned with my work, I felt really the only reason that I was doing it was to prove myself that I was good and that I have the acceptance of the people I worked with and that's fine, that's good, but there has to be a larger picture ... for me I have to feel like I'm affecting positive change, you know I've said that before but I feel that is really important.

For Gerry, his role as a board member brings the satisfaction of knowing he has helped other people by producing tangible results at board level.

When asked Gerry to sum up his experiences in a phrase or word he stated that "it's been pretty positive you know, I've made a very good friend through my experience there ... it's just the human contact I enjoy." Gerry's role on the board has helped reduce feelings of isolation and subsequently increase the amount of support he receives.

Chris participates on a number of boards and committees including a mental health agency and hospital board, as well as advisory committees. When asked how she became involved with board and committee work, Chris said it started when she was at an all time low in her life, she was recently divorced and had no friends and family. She was also ill at
the time, in hospital, and the nurses at the psychiatric ward took care of her. There was a mental health agency in the process of reforming in the area and one of the psychiatric nurses took her to one of the board meetings. Chris began to go to the board meetings periodically, however, she eventually became more involved and started advocating for better mental health facilities for consumers in the area. Chris stated that at this point she "didn't have anything to lose." Her advocating finally paid off and new facilities were built. From there Chris said she became more and more involved and began assuming a number of positions on the board. After many years of involvement, it appears that Chris is sought after for board and committee work. In fact, it is at the point now where people expect her to be involved which can sometimes be frustrating. "One of the big problems I see of the consumer movement is that people expect you to do things and now that people expect me that irritates me ... I mean when people on the nominating [committee], put me on the nomination committee and I didn't know until I got a conference call, that irritates me."

Chris appears to be very passionate about her work and derives great satisfaction from being able to help others. She appears to be well experienced with the political nature of board and committee work and seems to have found effective ways to cope with the stress. When I asked Chris what she would miss most she replied "just the friendships." For Chris, like many of the other participants, the opportunity to meet and get to know other people is a valued thing.

In summing up her experiences on boards and committees Chris had this to say for her many years of experience - "wonderful opportunities". Overall, it appears that despite some of her negatives experiences with board work, it has been beneficial to be involved.
Rob

Rob is involved with provincial, regional, municipal, advisory councils, consumer, agency, and hospital boards.

He began when he was participating with a mental health agency and began doing some advocacy work for people with a mental illness. He said, "I was sort of in my early days of college before I even joined the board I was sort of a self-appointed advocate for people." Soon he found himself appointed to an mental health agency board and attributes this to mandates from government to consult consumers regarding the services in the mental health system. In the beginning he said he was appointed to most boards and committees he participated on because of his growing reputation. He said he "developed a name for stuff like that," and was recruited for additional committees, many of which he was the first consumer participant. As an advocate he continued to speak up on issues affecting consumers, became more well known, participated on more committees and this pattern continued for some time. Today he is a sought after as an advocate for people with a mental illness.

Rob is passionate about his advocacy for equality for people with a mental illness. He derives a sense of meaning and contribution from his work on boards and committees. When asked what he would miss most about his work on boards and committees he said, "I would miss the power, the power to be able to make a difference in people’s lives.... being in on the decision making process ... I would miss the relationships too." For Rob, the ability to affect change is a powerful motivator.

In summing up his experiences Rob offered the following:
At the beginning it was one step forwards and two backward, I think what we’ve managed to attain to this point is two steps forward and one step backwards, I mean we’re not all the way there yet but certainly I think we’re doing a lot better, we’ve made progress, I mean they’ll never, never be you know, quick enough for me because I’m very impatient, I mean and see I guess I’ve always had a problem, like I’m willing to engage in the process but I’ve always had a problem in trying to attain rights for myself and for people that I represent, when those rights were granted to me as my birth right and yet I find out that I have to fight harder than anybody else for them.

Rob’s involvement with boards and committees is one way he is trying to attain equality for people with a mental illness.

Jory

Jory was the only participant who was involved in a committee that consisted of only consumers. When asked how she became involved with the committee she participates on, Jory recalled the time she lost her job because of her mental illness and her inability to cope with the demands of the position. She was hospitalized and remembers being in denial about her illness. She wanted to continue working but in reality she could not, and has not been able to so far. During the interview Jory discussed a lot about her past job, what she did and what it meant to her. The impact of the loss of her job on her life has been great. Working allowed Jory to contribute and make a difference in the lives of others.

When Jory was first hospitalized for her illness she had a long stay and felt that she "was being used in the mental health business". She felt mistreated and that she was a political toy
for the nurses. "I resented that, I got angry, I felt like a pawn being sacrificed in some giant chess game." Jory went in and out of hospital for some years until one time where she was released and became connected with the local mental health centre. From the doctor at the centre she heard about an outreach program and asked if she could join one of the groups. Subsequently, the nurses at the mental health centre and outreach group were in contact with an outside mental health committee. It was through the nurses that she was eventually recruited to participate on a committee. Jory has remained involved with this committee for a couple of years and despite her leave of absence, plans to remain involved.

It appeared that her participation on the committee plays an important role in Jory’s life. Once more Jory feels productive and that she is able to contribute and utilize her many skills. Her committee role has given her an opportunity to be with many other consumers and to decrease her alienation. When asked what she would miss most from her committee work she said, "I think I would miss most the comradeship, it’s like a bond I guess, where I would feel safe with them." The committee is made up mostly of consumers which may lend itself to the solidarity that she feels.

In summarizing her experiences Jory said, "I would say that my [psychosocial] type skills have become alive, my health has improved". Participating on the committee has provided Jory with an opportunity to regain elements of her personhood while she deals with her mental illness.

Summary

The stories of how each of the nine participants became involved with board and committee work bear many similarities yet each possess its own uniqueness. There was a
degree of commonality among some of the participants as to what they would miss most, such as friendships and the ability to affect change. Each participant also summarized their experiences over the years which ranged from fulfilment, to acceptance of one's illness, to attaining new opportunities. While there are many similarities among the participants, their stories were offered so as to highlight their individuality. The next part of the results will focus on common themes of experience among the participants on boards and committees within the mental health system.

**Description of the Common Themes of Experience**

The findings of this study indicate that the experiences of participants on boards and committees are multifaceted and dynamic. Common themes of these experiences can be drawn from the participants' accounts. Each theme is presented separately, however, they are all interwoven and no one theme can be set apart as being the most significant. The common themes are presented to foster a better understanding of the participants experience of board and committee work. In the remainder of this chapter eight themes and four subthemes that emerged from the analysis of the interview transcripts will be presented.

**Common Themes**

The participants reported an equal number of positive and negative experiences on boards and committees. The following themes and sub-themes emerged from the participants' descriptions of their experiences:

1. The experience of making a contribution or helping others through boards and committees.

2. The experience of being responsible and accountable.
Subtheme: The experience of difficulty in being responsible or accountable.

3. The experience of a power differential or inequality between consumers and non-consumers on boards and committees.

Subtheme - The experience of being assertive for female participants.

4. The experience of positive outcomes:
   a) Friendship
   b) Empowerment
   c) Increased self esteem and confidence

5. The experience of disempowerment.

6. The experience of frustration.

7. The experience of feeling separate or different.

Subtheme: The experience of feeling uncomfortable when first joining boards and committees and then gradually settling in.

8. The experience of stress and exhaustion.

Sub-theme: The participants means of coping with the experience of stress, pressure and frustration.

In addition, many of the participants reported a shortage of consumers involved with boards and committees and offered suggestions for facilitating and improving consumer involvement which will be discussed following the common themes of experience.

An interesting finding emerged upon further analysis of the data regarding Jory’s experiences on boards and committees. She participates on only one council which is strictly comprised of consumers. Jory was not screened out in the initial selection of participants as
the literature does not suggest there are differences between consumer/non-consumer and all consumer boards and committees. Although Jory’s experiences bear many similarities to the other participants, she did not share all of the common themes, for example, the experience of a power differential between consumers and non-consumers. For this reason, Jory’s accounts may be absent from some of the themes.

In summary, the common themes among the participants’ experiences provide a picture of consumer involvement on boards and committees. The focus of this chapter is to explore each of these themes through the eyes of participants. They will be directly quoted to achieve a full understanding of their experience.

Presentation of the Accounts

The Experience of Making a Contribution or Helping Others Through Boards and Committees

“It’s nice to feel like I’m contributing to something you know, something I feel is important.” - Gerry

Each participant shared the common experience of making a contribution as board and committee members. The sense of making a contribution is experienced as believing their participation is helping their board or committee to meet its goals. Many participants believe their involvement contributes to the welfare of other consumers and to positive changes within the mental health system. For some participants the expected sense of contribution is an attractive part of board and committee work. The participants experienced a sense of contribution from a variety of actions and outcomes like offering a client perspective and developing programs for other consumers. They also believed they were helping to better
the mental health system. The feeling of making a contribution was also expressed in terms of rebelling against the system by two participants. Other consumers provided examples of times they had contributed and experienced meaningful participation such as when helping other consumers, or board members, or solving a problem issue on the board. Furthermore, many participants experienced contribution in terms of helping other consumers and bringing about change. All participants shared this common experience despite the length of time involved on boards and committees. Overall, the participants experienced their contributions as meaningful and that they made a difference.

Many participants stated that they wanted to experience the sense of contribution as part of their board and committee work. As Rob explains, his involvement is about contribution and altering the stereotype that suggests consumers can't be contributors:

I mean, cause we don’t expect to be given anything, I mean part of the fact that a lot of consumers are considered to be takers, rather than contributors, I mean, it’s our responsibility to wipe out that image, to show people that we have something to contribute and that we’re useful, functional human beings, and I’m not talking about, you know, cleaning people’s toilets and serving coffee, right, I’m talking about actually participating in the process and bringing something to it.

Both Jim and Mark echo Rob’s view. They want to experience the sense of contribution by knowing that their involvement will help other consumers. For Jim the experience of making a contribution to benefit other consumers was expressed as "the feeling that somebody won’t have to go through what me or others have gone through." Mark states, “If I can help one person to keep from experiencing what I experience, [then], it makes it all worth it.” Jim
believes he can help other consumers by making a difference in the treatment they receive. For him, the motivation to help other consumers stems from his own past experiences and now he is in a position to ensure that no one has to deal with what he did. As Jim states, he is “I always get the feeling like you know, I know what it feels like to feel you are the most pathetic piece of person on earth, and then to have someone defend you and validate you is like wow what a feeling.” Mark on the other hand discusses the expectation of contribution in terms of what he might miss if he were no longer involved with boards and committees. “Say if I drop out tomorrow and get back into it a year and a half or two years later, those same opportunities won’t be there because they would have already been dealt with right, or whereas somebody else might have already changed them and or started something or whatever.” Both Mark and Jim are attracted to boards and committees due to their strong belief that they can make a contribution that will benefit other consumers.

Gerry is similar to Mark and Jim in that he shares the expectation for making a contribution to the welfare of consumers through board and committee work. One of the reasons that Gerry joined the board he currently sits on is he saw it as a vehicle through which he could contribute, and consequently help affect change for consumers and mental health system. Specifically, Gerry was attracted to boards and committees because they avoid the antagonism between consumers and non-consumer stakeholder groups while bringing about these changes:

With a growing consumer voice, there tends to be a polarization that, and this happens with all sorts of political happenings not just the mental health deal, ... I think there is a tendency for people with a like orientation to get together, we’re strength in numbers,
and then they develop an identity which is separate from the rest of the world and the political camps tend to polarize, so you get, so what can happen is that you get consumers on one pole and then mental health workers in another pole, which is something, which is really a bad situation, ... and this is the reason that I wanted to try and get involved through the established structure, like through an [organization] ... I wanted to get involved through the established structure and try and work change through the system that has been set up, ... rather than having it be a power play and just a lot of consumers get involved and say, look you people just don't understand at all.”

Gerry believes he is able to share his knowledge and experiences within the structure of a board and this will ultimately increase the chances of bringing about change for consumers.

In addition, Gerry states the expectation of contribution is shared among all board members with whom he participates. "The hope that everybody has is that at the end of the meeting, or at the end of a succession of meetings, we're going to have developed something concrete, something lasting and something that is going to make a difference in the lives of consumers.” Nancy echoed this view and said she is working towards, “a better system of care and help create a system where consumers will have less difficulty in the future.”

Similarly, Rob’s goal is to assist in the creation of a better system of care and to support other consumers in their efforts. Rob stated that his role as an advocate offers personal advantages to him, however, he said, “but I also do the things I do because I believe, I believe in what I’m doing, I have a passion for the underdog.”

Like other consumers, Nancy was first attracted to board and committee due to her belief that she would be able to contribute to the development of quality services for people with a
mental illness. Nancy said, "I was frustrated with the fact that so many people did not understand the difference between a mental handicap and a mental illness and I thought I want to make sure that these services that they’re describing, it’s the mental health services are the right thing, and so I went and that’s when I got involved.” For other consumers, their involvement is about a long term plan to help bring about change in the way consumers are treated. Rob stated “in our life time we are not going to see the ideal conditions that we envision now and we are sort of pioneers in that movement and that the benefits will only be derived maybe the generation to come of the generation after that.” On the whole, it appears that Rob, Gerry, Nancy, Jim and Mark were attracted to board and committee work due to the anticipated experience that they could make a contribution for other consumers.

The participants were specific in terms of the kind of contribution they felt they were making at board and committee level. There were two types of contribution, that of providing a consumer perspective and of developing programs. Both Gerry and Mary shared a belief that they were contributing by providing a client perspective on their board or committee. Gerry feels he contributes to his board a client perspective of the mental health system. "Everybody has their own skill set, everyone has their own things that they are good at, some people are very good at going to rubbing shoulders with important people and making conversation, and I've never been good at that you know, but I do think that I serve a role in bringing a client's perspective to the board." Mary also believes that she provides a consumer perspective on some of the issues brought up on her committees. “I pay attention you know, most of the time to what’s happening, and I always talk about consumers and I always bring that word in or ... what people might want to do right.” According to Gerry,
the insight that he can provide because of his mental health background is a valuable commodity that he is willing and ready to share, "I speak from my own experience a lot of the time, because that's my perspective, that's all I can really contribute is my own perspective." On the whole, both Gerry and Mary believe the kind of contribution they make at board and committee level centres around the client perspective that they offer.

The other type of contribution the participants felt they made at board and committee level dealt with the development of programs that benefit people with a mental illness. Part of Chris' contribution on boards and committees has been to develop various programs. When she first started, "we didn't have a lot of programs, I developed some programs and started another [project]." She described with a quiet sense of pride the various projects she had been involved with and how these projects have made a difference in the lives of other consumers. Similarly, Mark discussed the peer tutoring program which he had been able to contribute to in terms of its development. The program entailed the training of consumers to assume a peer counselling position with other consumers:

This peer counselling thing, I went to a meeting, ... I was one of the three consumers there and, they were yammering on about this and that and the other thing, and I said well why don't we get a peer counsellor or start a peer counselling thing and it end up now, somebody [has] been hired to develop the training package, consumers are being interviewed for the course, I mean that's maybe nobody but a few people remember that I'm the one that suggested it.

Like Chris, Mark believes he made a contribution to the committee and in the end to consumers as a whole. Overall, the participants felt they were able to make a contribution in
the development of programs that benefit consumers.

In discussing their involvement on boards and committees, the participants talked about how they experienced a sense of contribution through their work, and how it benefited consumers and the mental health system. Jory stated, "I think I really have made a difference, I'm very quiet on the council, I don't want to offend them and I don't want to put them down, and I just want to contribute to their successes." Julie asserted that when she leaves the board she will have made a substantial contribution to some of the organization's policies. "I could in a year walk away from the board and say, what was there that wasn't there when I got on there was, you know a set of guidelines that are helping to shape the way the organization goes and that's something you know." Gerry stated that he enjoys knowing he has contributed to the betterment of services for consumers despite that it can sometimes be a lot of work. "It's a burden which I take with a certain sense of enjoyment because I feel like it's doing something positive, it's working towards positive change."

Furthermore, Mary experiences a sense of contribution when thinking about the benefits her participation has for other consumers. She feels her presence on the board paves the way for other consumers to be involved in the decision making process which is evident in the following analogy. "I feel like ... the thing about the Canada geese right and how one goose always takes the lead and bears the wind and does that and then they move over and then this other bird comes up and, and I figure that's the position I'm in right now, I'm in this position for other people and so, ... that's why I'm there." Mary also stated, "I'm doing it ... for the change for the consumers, I'm not doing it for the change on the board."

Both Jim and Rob expressed the sense of making a contribution in terms of rebellion and
being able to make a difference. For example, for Jim there is a strong sense of rebellion, of contributing to a cause, "it's like we the people against the system and you know, I feel good about that you know, not a lot of places offer consumer driven services." Rob also wants to feel like he is making a difference for the benefit of consumers, he says, "what's in it for me is by being able to make a difference, ... I mean if they told me I wasn't allowed in the board room anymore I wouldn't be able to still make a difference in people's lives."

Furthermore, Jim compares his involvement to the hippie movement, a time of change and of challenging the status quo. In Jim's case the status quo is the mental health system and he is out to challenge its oppression of consumers. "I guess it's like the hippie movement (laughs), it's like you either think of it as that you know, there [were] the hippies and they felt that they had to go and control the government to stop the war." Jim's choice of words, "rebellion", and "hippies", exemplify his experience of contribution by affecting change.

Specific Examples of Contribution

Not only did participants discuss how they believed they had made a contribution, they also provide examples of when they had experienced it. In the days before Jory became ill she had a career in the helping profession in which she contributed to the development of others. Jory has been unable to return to this occupation because of her illness. Board and committee work enables her to experience that she can still help others to grow and learn, specifically consumers. An example of when she experienced the sense of making a contribution involved a dance that she helped organize:

I can dance a bit, and I've got a little more confidence and I can get other people up dancing and have that social skill that they don't have, and a lot of them are shy or they
won't know each other so they'll be at this other [place] ... I know I can have a good
time in helping them to learn how to socialize and get them back into a pattern, or a
cycle or wellness again cause I've been there.

Another project she worked on illuminated her experience of making a contribution or
helping consumers. As part of her role on her committee Jory organized a one time forum
for consumers to discuss issues that were important to them. In talking about how the day
transpired, her experience of making a difference emerged:

I was very proud of them because I sat there, I participated very little, I let, I
encouraged them, just like [my past job] that was getting her [participants] to perform I
fall into the mode quite easily and I just had to sit back and as each one of them talked,
I'd give them good feedback and that brought more of the other ones out so that they
talked a lot, they participated, they felt good about participating, I know, and they also
felt good, they had a say.

Jory feels a sense of contribution and meaningful participation when she helps other
consumers as part of her role on boards and committees.

Similarly, Rob experienced a sense of contribution by helping win a battle for consumers
on a council he was involved with. By working with others and persevering he was able to
prevent money being cut for consumers who participate on boards and committees:

We've been working with the [council], and you know, the ministry has said that the
money was cut off and we weren't going to be able to pay honorariums, for people, you
know, that attended the meetings. And they just sort of said well no more money, we
don't care what you say. Took three months, three months of board meetings and a lot of
aggravation and a lot of taking on people at mental health services but the end of three months we had the honorariums for people ... what we ended up [with] is not just people being paid [a] hundred dollars a meeting, but also something we call continuous involvement for serving on other committees and while I wasn’t the sole determining factor in there, I stuck in there with a couple of other people and we like we had to face off the mental health services and they finally agreed to because they couldn’t handle it any more, because they couldn’t justify it because I mean, every argument that they put out there, we meet them with, and at the end of three months where you’re talking about 24 hours of meetings, we got what we wanted.

An example of when Julie experienced the sense of contribution involved a time she helped her fellow board members crystallize their views towards an action plan that they had been working on. Julie had gone to the head of the organization she represented with some of the concerns she had regarding the nature of the policies the board dealt with. In discussing her issues with this individual she was able to formulate what she wanted to see happen on the board, she said “it was like a light bulb went on.” A little later at a retreat the board was having, they were discussing the action plan for the organization. Many of the members were uncomfortable with the plan despite the fact that they had worked on it for some time. Subsequently, Julie shared the insight she had developed and this helped the other board members look at the plan differently and from this she derived a sense of contribution:

We had all gotten together in this retreat situation and [came] up with an action plan, and we had been doodling around with it for months and finally we had a meeting and this all sort of happened around the time of this meeting where we were going in to decide okay
are we going to toss it out, everybody I think felt a little bit uncomfortable with this action plan because it was still operational stuff it wasn't policy stuff and yet, so how do you make it policy stuff, how do you, you know what are we going to do with it, and then when I crystallized my own issues I think that it helped other people to crystallize their’s and a lot of discussion happened, we pitched that action plan and you know, on our own came up with another one that I think really did work more with the model we were supposed to follow, still dealing with issues that were close to our hearts, so that was a real breakthrough for me.

Julie experienced the sense of contribution when she offered her own learning to the other board members which impacted on their views towards the action plan and its further development. Up to this point in time she hadn’t felt that she was effective in bringing about change, however, this event helped alter her experience to one of meaningful contribution.

An example of when Chris experienced the feeling that she had made a contribution involved a committee meeting that was dealing with the issue of representation. Despite the difficulties she encountered, she was able to contribute to the final outcome and change the way the other members looked at the issue:

It wasn’t long ago I was on the [committee] and there was a lawyer, there was the executive director, there was another consumer, there was a fellow who is high up in education and myself and we were on the [committee] and the lawyer had brought out this thing about having delegates and the way it worked out for voting, ... the way it worked out was very unfair representation for Vancouver, and me, I’ve talked about the middle of the road before, I like fairness, it’s just ingrained okay, ... I finally wrote to
him and said this isn’t going to work, this isn’t fair, this is really unfair representation for Vancouver, see like the smaller centres were going to get exactly the same as what Vancouver had, that doesn’t make sense ... so anyway I wrote it out and I wrote, and I went to [Steve’s] office and asked them to type it out for me, so they type it out, and then I went back home, I woke up about three o’clock in the morning and it dawned on me what I should do, ... I figured it out that way, on the bell curve how it would work, with 25 votes and 50 votes, ... and so what it worked out that the smaller branches got one bigger or one more representative and the bigger got one less because the way it worked with your 75 and 100 and then it they were over say a 150 they got one more delegate, but it wasn’t even but it balanced the fairness, it balanced it fair, so anyway I sent the fax off, they still didn’t understand it and then I talked to them and then they said, “oh gee, we’re glad you were a burr in our asses!”

Gerry also described a time where he felt he had made a contribution to his board.

“When I reach inside myself to try and articulate truth, and then I am able to articulate it, and I look around the table, and I can sense from the other people that they have appreciated what I have said and that they felt that it’s appropriate and they are willing to adopt it into the general game plan.”

In summary, the participants experiences on boards and committees involve the sense of being able to make a contribution to the work of the committee or to other consumers. For some participants the perception of being able to make a contribution was one of the reasons they were attracted to board and committee work. Other participants discussed the types of contributions they made such as offering a client perspective or developing programs.
Furthermore, some participants shared the ways in which they experienced the sense of contribution and meaningful participation with some specific examples such as helping consumers, other board members, and moving ahead an issue on the board. Overall, a common theme emerged among the participant's accounts that involved the sense of being able to make a contribution to their board, committee, or to other consumers.

**The Experience of Being Responsible or Accountable**

"As a consumer voice I take very keenly my responsibility for the fact that I'm speaking on behalf of a number of people in the community who may want to avail themselves of these services." - Gerry

The participants shared a common experience of feeling responsible or accountable for their actions to other consumers or board members in their role of consumer representative on boards and committees. Many participants felt they were charged with the responsibility of representing and providing the consumer perspective on the board or committee. The strong sense of loyalty and responsibility to the consumer stakeholder group also emerged. The examples offered by the participants of being responsible or accountable ranged from providing a client perspective, soliciting the views of other consumers, to being held liable for various duties on the board or committee. Some of the duties included providing tension on the committee, breaking down stereotypes, roles of chairperson and treasurer, and finding consumer replacements. Furthermore, a participant discussed how she would like to be more responsible in the future. The participants shared the belief that the role they were entrusted with on boards and committees was an important one and that they needed to be trustworthy in this position.
The subtheme found within this theme is the experience of difficulty in being responsible or accountable. The sub-theme deals with the difficulties that were experienced by the participants in fulfilling their role of being responsible.

**Responsible for Portraying the Needs of Consumers**

Many participants accepted their duties as representatives in portraying the needs of consumers and felt they had to be accountable for their actions to their board or other consumers. For Gerry the importance of being responsible in representing consumers emerged after he joined his board:

> I really did feel though after being involved with it for a short while that really, that this was a very important, type of position, especially for somebody with my background, a very important opportunity to voice concerns and to have them recognized and understood and heard, and actually see policy changed, to meet these concerns ... I see it much more as a working thing or something that is really quite important.

Mary also sees being responsible as keeping the needs of consumers in the forefront when representing consumers on boards and committees. “I have to remember people who are not there .... I’m there representing other consumers.” An example of when Mary felt she was being responsible involved a board meeting where she felt the consumer perspective was being ignored:

> The last time I came out here for a meeting this woman had gone around and she had gotten permission from consumers about their problems with [services], ... and the first one was general practionners, and then there was quotes in there that people who had been feeling suicidal had gone and seen their doctor and their doctor had said, “Well
have a cup of tea,” you know, “I’m feeling suicidal doctor,” “well maybe things aren’t as bad all that, why don’t you just go and you know and have a cup of tea,” people put down ... I could go off on this tangent but I won’t, anyhow, this was this thing that this woman had gone out and she had complied all this information so what did we do? We sat around for 20 minutes discussing the problems of the doctors, in dealing with consumers that you know, well consumers well we take up more time than the average visit, patient, that doctors are not really educated, that comes to me as a surprise cause I thought that doctors were supposed to be at least a bit knowledgeable about what I was going through, and every time I’ll bring up something, I said like well we spent 20 minutes at this meeting talking about the MD’s problems, not the consumers problems right, and I can almost see people rolling their eyes right, but that’s what I’m there for, I’m there to make them aware of this is what it is like, not what it is like to be a consumer but the issues that consumers might have.

Nancy also echoed Mary’s view in being responsible for representing the needs of consumers. “I emphasize at [my organization] that my role and purpose there is to represent consumers although I have an obligation to the organization.” In representing consumers on boards and committees she feels the need to consider a range of views before making a final decision:

Like I can’t speak for all mental health consumers and if one group has one opinion and one group has another then I have to say that’s one opinion, that’s another opinion and I’m inclined to buy into this idea, personally, but there are other opinions, ... so you have to bring forward sort of what you might see, ... otherwise you’re not truly
representing people and then it's up to the rest of the group to make the decision.

Mark also sees the need to be responsible in representing the needs of consumers. For example, in deciding between two committee meetings that he had to attend at the same time, he made his decision based on which committee it would be important to have consumer representation at:

I got a lot of shit to do, a lot of these are conflicting, for instance the committee [A] ... conflicted with the committee [B] and so I looked at it and said I am going to go to the committee [A], not because it pays but because I have obligations, I've been designated one of the [organization] representatives, it's more important than this committee [B] because I am one of the only consumers, this is one of the first times consumers have been asked to participate.

Mark felt the most responsible thing to do would be to attend committee B because it would help carve an inroad to a place consumers have not been traditionally invited to.

Chris also has a very strong loyalty to consumers and says that her "focus is the consumer." A recent example of her experience of responsibility for representing the welfare of consumers arose when the administrator she worked with was exploiting consumers:

You know our Administrator tried to devise a vocational program which is highly inappropriate for consumers, his initial aim was to make [the organization] self sufficient, and he in the process, he would be exploiting consumers because they would be paying off the debt for 6 dollars an hour, if there was a profit, if there wasn’t a profit they wouldn’t earn anything so you know that’s not the approach, that’s not the
rehabilitation approach at all.

For Chris this situation has been intolerable because of her feeling of responsibility to consumers. In response she has started writing a manual so that other board members will know about rehabilitation methods thereby protecting consumers:

I mean that’s one reason I’m writing this manual so that people can read it, so the board can read it, what should be happening you know, because they don’t know, they just say of, yeah, well, sounds good to me we’re going to employ consumers, well you don’t set them up for failure and that’s what’s happening, you know this one fellow, he can hardly even talk and he’s got him going to do this, and I mean at first these people didn’t understand, and they thought they were working full time, and they went through hell because this was expected of them.

Chris experiences a sense of loyalty and responsibility for representing the needs of other consumers in her organization.

Similarly, Rob experiences a need to be responsible in providing a consumer perspective on issues:

I’m expected to delivered on some level and that’s something new for consumers, I mean most of the time you sat at tables and nobody really expected anything from you, I mean you just sit there and say yes and no once in awhile. Now people, I mean I’ve sat at meetings where I didn’t say a word, and I have had people actually try and draw me out and say, “well, you know we need to hear what you have to say on this because you are the consumer person here right,” .... what I like is the fact that I’m expected to be there and that I’m expected to do my share ... and there’s realistic expectations, nobody’s
asking me to come across as a Ph.D there you know [instead] asking me to come across as a consumer advocate which is in essence what I am.

A specific example of when he felt under obligation to provide a consumer perspective was offered in one of Rob's experiences where the committee was trying to decide where to locate a new boarding home for consumers:

Well, what [was] happening was we were meeting with a municipal committee or with city council, on a re-development project for a housing project here and the neighbourhood had been very adamant that they didn't want you know a psych facility in their neighbourhood, and I was the only consumer sitting on the steering committee, and I didn't say anything because I was, I was, it was really, it was a tough call for me, cause most of the opposition was coming from, sort of the elementary school because they didn't want a facility for chronic sexual offenders in their neighbourhood and the funny thing was I didn't know where I stood on that because I, I'm very sensitive to people that molest children ... and I don't like the fact that people seem to think that people with mental illness are also sexual deviants, right, and so I didn't want to be lumped together so I sat there for three hours and tried to process all this. And then, you know I hadn't said anything and you know, city council just dumped this back and forth and the mental health professionals that were there, and finally, the city, the [chair person] ... said, “you have to help us here,” she says, “you haven't said a word for three hours,” ... and so I said you know I was just trying to figure out where I stood on this. And I said, “what I would do is,” I said, “I would advocate that everybody has a right to live in the community,” but I said, “what would need to happen,” and nobody
had asked about this to this point and nobody considered it, I said, "I would have a town meeting and a community consultation to find out exactly what people did, not at city council, but out, you know in the community where mental health advocates and mental health professionals could speak to the community members." What happened was is that they went ahead and did that and the facility got into the neighbourhood and everybody was happy because we had suggested that there be a rigid screening process put in place so that the people who were going to be ready to be live in the community and that there would be adequate, there would be adequate response, you know to neighbourhood concerns like if somebody acted out of you know, in a inappropriate manner that police would respond. Because we covered all those bases, the community excepted them.

Rob has experienced being called on to provide a consumer perspective at meetings and on the whole, a lot of the participants have experienced feeling responsible or accountable for representing the needs of consumers at board and committee level.

Responsible for Soliciting the Views of Consumers

Another area that the participants felt responsible or accountable for was that of soliciting the views of other consumers to bring to boards and committees. For example, although Rob recognizes that he is a leader and represents the views of consumers, he feels an obligation to consult with the people whose needs he portrays:

I like calling my own shots you know but I don’t call shots for other people either, but if people put their faith in my ability to lead then I will make decisions for them based on consultation with them, I don’t make a move in my work I do without dealing with my ... committee first, you know and then they’ll say well go for it and then I’ll go and then
I'll this is what we're thinking you know.

The need to consult with consumers directly in order to achieve responsible representation at board and committee level was also echoed by Jim. When looking at his role of representative, he doesn't believe he can be an effective without soliciting the views of consumers. Jim said, "I noticed inside myself I wasn’t getting other [consumers] opinions, like how can I be a representative, for consumers if I’m not talking to other consumers when it’s just my own conscious right ... so I started calling and enquiring and they sent me up north and I went to, got to question some people." Like Rob, Jim believes that if he can solicit the views of people in his stakeholder group, the better able he is to meet the obligations of his role.

For Chris there was a need to find out different views on mental illness, however, unlike Rob and Jim, she chose to become aware of the needs of other consumers by educating herself about mental illness:

Most of my focus has been on bipolar because I am bipolar but now I’ve got a really good handle on schizophrenia, I started with the etiology of schizophrenia and sort of worked up to you know to pharmacology so that I could understand it and the trials and experiments and all this other kind of stuff that you work yourself up to understanding, but I’ve done quite a lot of reading.... so now schizophrenia is just 1% of the population, and I have a better handle on it so that I can go rather than just with my own experience. Chris believes her increased knowledge of specific mental illnesses makes her a more capable representative on boards and committees.

Responsible for Specific Board Duties
A final area that consumers said they experienced responsibility or accountability in were the duties that were part of their job as board and committee members. The responsibilities ranged from providing tension, breaking down stereotypes, positions of chair and treasurer, to choosing other consumers to join the committee. For example, Gerry felt very strongly that his duty on the board was to provide a source of tension that could move the board forward in their goals. He perceives himself as an effective board member when he is pushing and prodding other members on the board:

I think my role as a consumer on the board is to constantly be kind of a little bit like a needle to push, to prod forward and if I’m pushing too hard then I have to know when to relax, but it’s a state of dynamic tension which is there all the time, and I’m glad it is that way because it means that hopefully we are getting something done, out of that tension comes sort of resolution, some sort of progress.

For Gerry the state of tension is crucial to his being a responsible board member, in fact if it isn’t there then he feels he will no longer be an efficient board member and will step down:

The tendency is that when you have been on a board for a time you become one of the good old boys, you become part of the status quo, the tension disappears, you get together you talk about what you shot on the golf course rather than talking about the present problems and the mental health deal and I don’t want that to happen, as soon as that starts to happen, as soon as I get too comfortable on this board, I’m going to see that I’ve, I’ve done enough time there you know, I’ve fulfilled my purpose, because I don’t think, ... while we can get along comfortably as adults with each other I don’t think we’re there to just be buddies, if we do become buddies, well so much the better
but there are more important things to work on.

An example of Gerry's experience of being obligated to push and prod, or create a healthy tension on the board is evident in his interactions with one of the women on his board. "This [woman], I have felt at times that I that I've pushed too hard and her eyes become kind of glassed over and, I know that I've pushed things too far with her, but that's just part of the process, it doesn't bother me now the way it used to, I was nominated and I was elected to be there and I'm there for a reason." Gerry experiences the feeling of being obligated or responsible for ensuring that his actions propel the board towards making good decisions for the organization.

Julie feels that as a consumer board member it is incumbent upon her to counter the negative stereotypes of consumers that appear on the board. "I almost get the feeling that again it's fighting that stereotype that you're basically some kind of vegetable and you have no life outside of whatever you're doing with mental health .... one of the reasons why I keep it up is I, I really do feel it's important that society see it as an illness as opposed to some kind of going crazy or failing at some point." Julie feels compelled to guard against erroneous and damaging views that board members might hold in regards to consumers. “It’s just I’m here as some kind of watch dog in a way and as long as they don’t have these gross stereotypes of people and actually there have been a few meetings where I’ve had to say excuse me you know, I actually really resent what you just said or what you just implied there." When asked to provide an example of when she felt responsible to counter a negative stereotype she encountered, she related an experience where a board member commented on the mental stability of OJ Simpson:
When OJ Simpson was arrested and some people in the board room were sort of making remarks on I don’t remember exactly what the remarks were now, but that he was mentally ill or something like this but it was it was, sort of in jest you know it wasn’t like they were talking, and I just I just said, "Look, it’s one thing I want to make really clear is you know, he’s a violent man, he’s not mentally ill, he’s deviant you know, there’s a difference," and everybody you know quickly agreed that it was kind of a loose way to look at the situation, but it sort of appalled me that this was coming out of a board.

Julie is appalled by the stereotypes that exist regarding mental illness and is compelled them as part of her role on boards and committees.

Two other participants experienced a sense of responsibility and accountability due to their positions on the committees of chairperson and treasurer. For example, as chairperson, Nancy’s role is to involve consumers in the process, however, when this does not happen she feels the need to look at her own behaviour to determine how she is or isn’t fulfilling the responsibilities of chairperson:

As chairperson of this council … I’ve been examining myself the last few days, is what am I doing wrong that I can’t get people motivated to work on the council but everything comes down, so I end up doing it, so I’m going to start developing another strategy to try and get people more involved and of course you always have to look at sort of what is my fault and not there’s, you know am I willing to give, to give up this perceived power, I have a thing about being in control because I feel safer that way, but I’ve got to learn to give up control for their sake and to involve them and make sure that’s
The experience of being responsible for Nancy involved examining her own motives and ensuring that they were not interfering with her obligations as chairperson.

A further participant felt accountable in her position as Treasurer for the committee. Jory feels accountable for the books in balancing them and keeping them orderly. "I am the treasurer of the council and, ... the books are perfect, they balance, they're recorded, everything's written down." A description of her experiences as treasurer is offered by Jory and the sense of liability is evident:

Our chairman gives us a lot of support, she knows that I'm a good treasurer and that my books are balanced and kept up to date and I'm fair, I have trouble, ... I mean some consumers put in for a lot more money and sometimes I let it go through, like they put money for travel when they have a bus pass, occasionally this one does it … not since he's come on council, he wears clean clothes and he shaves or he cleans, like he takes care of himself better so now and he doesn't leave the garbage around all the way … I talked to him especially, but it's this fellow, and I see him as growing on one hand, but yet trying to get away with a little bit more all the time … the first time I didn't let him [get] away with it, I questioned him and made him write it out again bit he made it out for more so I gave him more and the next time [the Chair] spoke to him … and I would not give him anymore money so he still owes me two more travels.

Mark also feels responsible to fulfil a certain role when he is on the committee, "my obligation on the committee, my obligation is to pay attention, express myself, give my recommendations, make motions, you know and stuff like that." An example of when Mark
experienced the sense of accountability arose when he was recruiting another consumer to replace him on the committee. Mark felt compelled to refuse the individual because their view would not benefit consumers as a whole:

You know a lot of people say they are interested but you also got to look at where they’re coming from too, you know, I mean I’ve had people like this one guy that was being, over done by the committee, I mean he’s got totally different ideas than what I have ... so it’s hard to offer this guy my place when I know he has totally different views than I have, and I was the one asked to sit on the board, so if I, I offer the position to somebody else who’s got totally different ideas, you know what, that’s doesn’t go too well with me you know, ... well just for instance you know this guys says you know why don’t we open up the course to all everybody and the whole purpose of it was for consumer, was to train and eventually employ a few consumers, I mean why should I give him a position of power or input when he’s going to suggest something that I don’t believe in, right, something that I think is not for the betterment of the mentally ill people as a whole.

Interestingly enough, one of the participants provided some insight into an area in which she would like to feel more responsible. Julie sees herself being more responsible on her board by utilizing her skills, not just her experiences as a consumer. For some time now Julie has felt she has been placed in a consumer role and can not offer more than her sad story as a person with a mental illness:

It’ll be interesting to see what the next year brings because I do feel more comfortable in the organization, I do feel like I have a role to play outside of consumer now, and
whether I’ll be able to sustain that and how other people will accommodate that sort of remains to be seen, I think there are a few fights ahead in just, I think that there are some in particular the stereotype about what skills you bring to the board you know that I really want to address head on, and I think that might be kind of messy at some point, but again that’s what I’m there for you know, I really I really want to do that you know .... I just need to stand up to that, I really need to challenge that, maybe because I’m a good board member.

Finally, the sense of responsibility and passion for helping consumers is seen in Chris’s following statement:

Once in awhile you get someone in there who does not have the best interest of the [organization] ... at heart, at least in my estimation they don’t and I think that [organization] has to find ways to work around this, there has to be a process so that people don’t have to bang their heads against walls, to accomplish this process because that’s not what ... it is all about, people with power, it is about empowerment, empowerment of the consumer which means, getting available resources and not to be blackmailed by these available resources to do what someone else wants for power ... there has to be a venue for the consumer for getting benefits from [an organization] and we have to keep working at it. We just have to keep working at it, and we can’t bury our heads in the sand when things seem too difficult and remember what we’re there for which is the consumer.

In summary, the participants experienced the sense of being responsible, or accountable to the consumers they represent as well as to the particular board or committee they serve
on. The sense of loyalty to the consumer stakeholder group was very strong. For each participant there were different experiences of being responsible, such as representing consumers, providing a client perspective, soliciting the views of others and being accountable because of their duties on the board or committee. Specifically, the participants felt accountable for providing tension on the committee, breaking down stereotypes, roles of chair and treasurer, and finding consumer replacements.

Sub-theme: The Experience of Difficulty in Being Responsible or Accountable

"Well at the point I felt disloyal, I felt I had sort of, I had betrayed another consumer and yet I felt I had no choice." - Rob

A majority of the participants experienced difficulties in fulfilling the obligations of their role as representatives on boards and committees. The barriers to being responsible were often those imposed by the external environment such as not being able to represent all the diverse views of consumers. One participant felt responsible for educating professionals and this was hard because some of them wouldn't listen. Further, participants experienced a lack of support from their committee members thereby making it difficult for them to do their job. Another participant found it hard to do his job because of the lack of technical support in understanding the documents. A couple of the participants experienced difficulty in being responsible due to internal barriers such as the pressure to perform and guilt over perceived betrayal to the consumer stakeholder group.

As reviewed prior, the participants felt a sense of responsibility and accountability in their role on boards and committees. However, the participants reported that sometimes external events or expectations interfered with them feeling responsible. For example, as
consumer representatives they were expected to portray the needs of all consumers. Gerry
and Julie reported this was a difficult if not impossible task because of the sheer number of
views possible. Gerry stated, "I guess it is a bit of a burden, I don't really view it as a
burden as much as I feel like I can't adequately express everybody's concerns." Julie stated
that the responsibility of illustrating the needs of consumers was one that was given to her
when she joined the board and this task has been difficult:

It's not like anybody says that directly but it's sort of a feeling you walk away with this
uncomfortable feeling after or that idea of being focussed on you know, so much that
you're made to feel like you've got the whole weight of the organization on your
shoulders, that somehow if you misinterpret something or if you stand up for your own
perspective too much somebody else is going to get left out, I mean you can't avoid that,
you only have your perspective you know, I just think it feels more uncomfortable when
you're a consumer because you feel the weight of all these people who need help, who
need assistance like that.... I don't want to act as some kind of interpreter.

Julie and Gerry have experienced the difficulty in meeting their responsibility to represent all
consumers. Like many other participants, Julie tries to represent as many consumers as
possible by meeting with them to discover their needs but she reports that this is difficult.
"I'm constantly sort of reality checking against other consumers trying to see if what my
opinions are reflected how other people who, who think the opposite or have another
perspective on it or whatever, and I find that difficult to do."

A further external problem encountered while trying to fulfil one's role as consumer rep
was that of feeling responsible in educating mental health professionals about mental illness


without any cooperation form the professionals. Mary stated that, “Like [Steve] comes to the [organization] and he talks about that as the role of the [organization] to go out and educate professionals about the realities of you know, of what people experience so, when I try and use that, like I said, I’m not listened to, so then I just think why am I even being here.”

Other participants experience external pressure in being responsible due to a lack of support. Both Nancy and Chris have experienced not being supported by their committee members which makes it difficult for them to be responsible in their role. Nancy experiences difficulty in being charged with the responsibility of being a chairperson because she is in the spotlight and feels others can attack her. A specific time when she experienced such difficulty involved a committee meeting where she voiced some views and others misperceived her actions:

There were accusations of me being in conflict, of trying to feather my own nest and really what I was doing was championing the issues of these people on the committee who did not have the courage to speak for themselves and so I think, and this is going to sound like I’m whining, it’s the truth, I have taken on a lot of people’s positions without their support and it’s been perceived as there are my issues and that I’m just trying to cause trouble and the unfortunate part is as I sit around those tables, the consumers who agree with me, or have, agree in the hallways, but in the meeting they sit there and hang their heads and there’s no support shown.

Like Nancy, the lack of support was also echoed by Chris in her experiences. In discussing her endeavours to protect consumers in her organization from the poorly run
programs her Administrator has set up, she experiences difficulty because no one is helping her. "When they tell you well he’s such a powerful man, he isn’t such a powerful man you know, I mean when I see all the holes that he’s got and, and nobody, it’s just what bothers me is nobody wants to take it on, nobody wants any problems, you know, let the organization fall apart, then somebody will do something about it." Chris feels she is bearing the responsibility of preventing the administrator from harming the consumers and this is difficult to do alone. On the whole both Chris and Nancy experience an external difficulty in trying to be responsible board and committee members of lack of support from others.

A further participant experiences difficulty in being responsible in his role of consumer representative because he can’t always understand the language in the documents and be prepared for meetings. Mark stated:

I mean aside from the meeting there’s all this information that comes by your doorstep with regards to the next meeting, it just boggles my mind ... it’s all in bureaucratisé or technical garb or a bunch of crap that just doesn’t mean anything to me .... and then you know I was on [a committee] when [Stan Smith] was Deputy Minister, and I, I really liked [Stan Smith], I really thought he was down to earth human being who wanted to converse with consumers so I, I conversed with him at breaks, ... whereas [Jim Jones] I believe is the guy that took over his job, you know I could let him ramble on for days and I wouldn’t even understand what his last name was because ... he would say it some what that I wouldn’t understand it you know, it just goes over my head, ... I’d rather either not go or just zone out when he is speaking and that’s not right .... I really
try to pay attention, but I, what am I feeling, what am I experiencing, like a loss or a waste actually, cause you know, I get paid a certain amount of money to participate on some boards and I feel guilty not, you know, I look at Dr. whoever, they are right in there, they’ve read all the material, they understand it all, and they’re interacting, or they’re writing notes down or whatever, I can’t even understand the crap they read, they’ve given me to read.

Two of the participants also reported difficulties feeling responsible as board and committee members which stemmed from a personal source. Jim and Rob experienced difficulty due to internal pressure to perform as well as guilt over one’s actions. For example, Jim states that when he participates the pressure is there not to make any mistakes. In the end, this pressure interferes with his ability to be responsible because of his anxiety:

Well a lot of the committees that I sit on I am the youth representative so youth aren’t really recognized in today’s society so it’s like when I start talking about youth issues it’s sense of empowerment or control issue with me like youth are going to be represented and I get really sick caring about, I feel really good about it but them I start to feel ... wow, what’s going on here you know, what are other people thinking, what are they thinking of what I have just said, And you know, if they didn’t like it?

Conversely, Rob experiences difficulty in being responsible because of the role he plays on boards and committees that may sometimes involve criticizing another consumer. Rob states that, “one of my roles has always been since I’m one of the pioneers on the committee is to bridge the gap, you know, between you know, what is cool for consumers and what is cool for professionals ... because my role here is to educate people as to how we’re going to
get along here and how we’re going to level the playing field." A time when Rob was called
upon for this role resulted in negative feelings between him and another consumer and this
was difficult. Rob felt he was betraying the very same people he was trying to help and
represent:

We were at a very tense meeting, ... and a consumer came out and said that we were
that, they they expected to be treated differently, and that if they wanted to insult people
and swear at people then that should be okay, they shouldn’t be asked to leave and this
was a friend of mind that I had ... that’s been involved in the movement for five or six
years and I came out and well “no,” I said, “I can’t accept that,” I said you know, “you
can’t sit there and call somebody a stupid bitch and expect to get away with it,” and I
said, “you know we have a responsibility to behave like human beings here” ... and I
was chairing that committee, and I said, “you should leave and come back tomorrow,”
and I said, “ready to apologize and you’re not coming back,” and what happened was is
that this person got all upset and walked out and never came back.” And you know we
still don’t see eye to eye on anything, I mean there’s still a lot of bitterness, we don’t
talk to each other at all anymore ... and there are a lot of times when I wonder whether I
did the right thing or not and then I think about, I think back to it and I had to trust my
instincts ... and I’ve always believed that you got to put your money where your mouth
is and that consumers have the same kind of responsibility or they should be expected to
behave responsibly if we expect the professionals to sort of behave in a respectable and
responsible way .... well at the point I felt disloyal, I felt that I had sort of, I had
betrayed another consumer and yet I felt I had no choice.
In summary, the participants experience some difficulty in being responsible or accountable on their boards and committees. The difficulties stemmed from both external and internal sources. The difficulties varied from not being able to illustrate the needs of all consumers, lack of support, difficulties in understanding the documents, pressure to perform, and speaking against other consumers. Nonetheless, the participants shared the common experience of difficulty in meeting the obligations of their role at one point or another.

The Experience of a Power Differential or Inequality Between Consumers and Non-consumers on Boards and Committees.

“It’s not only not equal it’s slanted and it’s threatening and it’s very ominous at one end and that’s the end the consumers are playing.” - Nancy

The experience of inequality was a common theme among the participants on boards and committees. Many participants reported a power differential between themselves and the various mental health professionals with whom they worked, usually in favour of the non-consumers. One of the participants provided a rationale for such a difference. Another participant recognized the inequality in the very history of the organization she represented. There was a recognition of the difficulty and enormity of the task of altering the differences in power. The participants offered a variety of experiences to express the inequality they felt, for example differences in respect, being recognized and heard, as well as that of status and prestige. Many of the participants experienced unequal standards being applied to them in relation to non-consumers. One participant said that the power differential was not overt, rather, cleverly disguised but she was able to see through it. Furthermore, Mark and Jory provided perspectives on the power differentials on strictly consumer committees. Moreover,
it was also interesting to note the experiences of two participants who felt they were sometimes in a more powerful position on their board because of their consumer status. Overall, it is through the telling of their experiences that a deeper understanding of the inequality emerged as well as the effect of this difference on their participation on boards and committees.

The majority of participants reported that they experienced being on the less powerful side of the coin in comparison to other board members. According to Rob, the inequality between mental health professionals and consumers is part of the very fabric of society which he is working to change. “This is an illness that’s ingrained in our society and I mean [consumers have] just as much human as you are right, so we’re not really talking about you know taking over the world, we’re talking about being treated like human beings.” Rob believes that the inequality between non-consumers and consumers on boards and committees is also a function of the training mental health professionals receive which dictates such a power differential. Rob stated:

It’s also related to the perception that mental health consumers can’t compete at the same level with mental health professionals, and it’s not just based on the fact that these folks think that they’re educated and better than anybody else, they, they’re more comfortable with the traditional power hierarchy, the hierarchy right, where I’m the professional and you do what I say and I know what’s best for you, and they’re not used to an equal exchange of ideas right so as much as that is for us, as difficult for us to make an adjustment, for the professionals, it is as difficult for them to make the adjustment because they have to change radically the way that they’ve thought ... they have to go
against everything that they've ever been led to believe.

Julie also sees that the power differential has been around for some time as reflected in the operation of the organization with which she is a board member. Julie stated that her current research of the organization has revealed that consumers have not traditionally been in positions of power but this was now a goal of the board and agency:

I mean I'm doing some research now on the history of the organization and things like that, and I'm getting the sense partly because it's such a big organization that it really is a top down kind of thing, even though it struggles very much to be bottom up, I don't think it's quite working that way yet I think that it is kind of an elitist organization so I think there is a struggle in it to make it more tangible for people, I think that the people want it to be, I think that, that's the ultimate goal at this point is to get more [consumers] involved actively in the organization because it affects them because it's dealing with issues that effect them but it will be difficult because I don't think it has been operating that way.

Julie recognizes the inequality in her organization although she seems comfortable with the attempts they are making to reduce it. Further ideology on the power differential between consumers and non-consumers was offered by Rob who sees it as a civil rights issue. Rob says, “nobody said that equality would ever be granted you know, over night, I mean look at all the people that have struggled for equality and how long it took them, when they are a lot of parallel movements right, you know, I mean look how, look at how long it took the woman's movement to get some respect, right they’re still not there, they’re still [being] discriminated against.” Both Rob and Julie recognize that reversing the typical power
A few participants reported that there were differences in power between themselves and non-consumers in terms of respect and recognition for ideas brought forward. They felt that professionals were taken more seriously or listened to because of their status and power in relation to consumers. For example, Nancy felt her views were not taken seriously on a committee until a non-consumer validated her viewpoint thereby giving her view credibility. “It wasn’t until somebody else other than a consumer came on side and recognized the problem, that they [began] to look at it, and seriously [without that] it was just a case of me receiving phone calls, and trying to get me to change my mind.” She added that, “the fact that the point was not taken valid until somebody else who was not a consumer, and is not a recipient of [welfare], validated it, and a professional so to speak, and I found that distressing but that was one of the few times that it really hit home to me.” Likewise, Mary found that consumers’ ideas were not taken as seriously as those that were offered by professionals, even if they happened to be the same ideas. Mary stated that, “people have told me that they have given an idea, and it’ll be ignored and then a professional will pick it up and then all of a sudden it’s like you know, oh the divine revelation has just descended, so even though it’s the same idea they’ll just, like they’ll grab onto it and because it’s a professional then they’ll be listened to … whereas when it was a consumer idea.”

Similarly, Rob experienced unequal terms of recognition between himself and the professionals on the board which he attributes to his position of inferior power as a consumer:
I mean if you’re gonna make judgements then make them after a certain amount of time, don’t assume though, that when a consumer walks into the room that they are not going to have to go off, and don’t be afraid to call on them … or recognize them when they put up their hand and ask to speak, when so often I see at meeting where people, you know, with very heavy duty names in the professional sector, they put up their hand, long after a consumer had their hand up and they get recognized first, that’s a respect issue, it’s also because the chair doesn’t seem, doesn’t think that the consumer has anything useful to offer, that has to change, I mean, they tried that with me a couple of times at the very beginning, but I just cut off the person that was taken ahead of me, I said, “wait a second, I said, I was here first,” I mean they’re not used to seeing that happen, because the chair said, “what’s your problem,” and I said, “well, I’m [not] gonna sit here like an idiot with my hand in the air for fifteen minutes and you’re not going to recognize me, I’m gonna go home.”

The inequality between consumers and non-consumers in being recognized is part of Rob’s experiences on boards and committees as well as that of Nancy and Mary. Mary states that the power differential between consumers and professionals on boards and committees can be equated to a “battlefield.” However, she said that the inequality is not completely overt, rather, it is subtle and can take on a variety of forms. Mary said, "I’m never, I’m never in the powerful position, because since I’ve, you know if I make a suggestion, it’s almost like, well it’s coming from this crazy, it’s not like that, they are much more urbane than that, they would never, not except on the streets would they say you’re crazy you’re nuts or something like this, these people don’t do that."
Another view on the inequality between consumers and non-consumers was offered in terms of the differences in power, status, and prestige. There was a recognition that the professionals have a higher financial status, occupation, and prestige on the board than the consumers which was upsetting to some of the participants. For example, Mark shared that he often feels inferior to others because of his consumer status and the attitudes of the professionals he works with. “I mean some people they try to make, the [board] they tried to, make me feel comfortable but they, they were a bunch of, past professionals that you know, one lady owned a boarding home for years that practised castration and neuterization you know, I mean how is she supposed to look at me after you know, 20 years of this, snip, snip you know.” Mark feels he is looked at as being inferior because of attitudes that are demeaning and place him in a position of little power. Likewise, Mary said that participating on committees is the same as asking ex-convicts to sit on committees with people who work in the correctional institution and counter the attitudes and power:

A huge issue for me, and it is a huge issue for me when I look at the psychiatric system, is it, is it, the huge differences in power right, and and even though I know that I am there to represent the [organization] and that I’m paid by [name of organization] exactly the same as everybody else is, and I have as much or whatever education, formal education as most of the people in the room, it’s part of being, it’s part of going through the psychiatric system right, I mean if you were asking people who had gone through jails to sit on a board of people who were in the system, well I mean you know just well, that’s really obvious, you know and that’s the same thing I have to deal with.

Like Mark and Mary, other participants recognized a power differential between
themselves and non-consumers due to differences in status and prestige. Jim said that he perceives that some non-consumers feel superior in relation to consumers on the committee. "I know they get, they, well high and mighty you know like it's an ego thing for them, it's about an ego trip ... it bothers me sometimes but not like I guess it doesn't nag at me, I can laugh at it to you know ... just like get off your high horse and grow up type of deal you know." An example of when Jim experienced this inequality involved a committee meeting where he wanted to leave and make a phone call but the Chairperson told him to sit down:

The chairperson of this committee like he's a doctor and that kind of thing, and you know he's all like sitting down and, "yup, okay, time to sit down everybody," and you know what they were talking about had no interest for me so I was going to go make a phone call and he says, "sit down Jim," you know, and just sat there or I sat down and then somebody decided to point it out to me and I don't know why I didn't think of it not pointed out to me, well you don't have to listen to him, go out and make you phone call right.

Jim was surprised by his reaction to obey the doctor at first. He attributes his actions to the power differential between the doctor and himself. Nancy has also experienced being on the lower end of the power scale in comparison to non-consumers. She often feels like she is struggling against this inequality, combatting "people, attitudes, a sense of ownership that people have of perhaps of us, and ownership of the system that we might perceive to be [consumers'] system as much as [non-consumers] system, because we're living the system, they're just designing it." For Nancy the inequality is experienced in people's attitudes and actions towards her that imply she is in an inferior position. For example, Nancy recalled a
time when she was told to take "no" for an answer by a non-consumer board member. She believed they were telling her she did not have a right to ask a question because of her inferior position:

I think even of those of us who are perceived to be the most powerful are still at the lower end, or just you know finding our way, and I had somebody say to me the other day that I had to learn not to take "no" for an answer from just one person, and I just thought this woman was so arrogant, ... you know doctors are gods, hospitals are gods and we must not question sort of thing, but when you’re talking about the community of mental health consumers, not only have they not learned yet not to take no for an answer, I would venture to say that probably 95 to 98 percent of the consumer population as not yet come to the realization that they have the right to ask a question, you know it’ll question the answer, and I think that that’s the state it’s at.

Chris also echoed the view that non-consumers hold more power by virtue of their socio-economic status, occupation, and even gender. Chris believes that this is something she faces in her experiences on boards and committees and needs to confront. "You are up against some pretty high-powered people, when I’m at [a hospital’s board] I mean I’m up against a lot of high powered people." Like Chris, Rob also sees the need to confront the power differential on his board:

This is a personal angle, I took on one of the more powerful people in the province at [and organization] cause he said one day about, you know that we should just be happy to be at the table and that I should just keep my mouth shut. And I said, “well,” I said, “I don’t think so,” I said you may be Chairman of this committee but I have an equal
voice at the table .... I may not be able to articulate in as eloquent terms as you do.”

Rob has experienced treatment from non-consumer board members that would suggest he is not an equal partner at the table.

An interesting view of the power differential due to status and prestige was offered by Mary who compared her experiences with inequality to that of the story of the Emperor’s new clothes. Mary says that people around her tell her she is imagining the experiences of inequality but she is adamant that she is not:

I don’t care if I’m in the hospital, or if I’m in the psychiatrist’s office, or I’m in these board room offices, there’s still the same thing, so the same power dynamics right that are going ... I mean if like you bring this up, you know this power thing, it’s totally denied, that can be crazy making right, for somebody who sees it ... I do live in a racist, sexist, class oppressive society ... everything is like the Emperor’s house the clothes ... the Emperor has no clothes and this is what is happening and you are not going to persuade me otherwise, you’ve not going to pull the wool over my eyes.

For Mary, the inequality is based on well founded personal experiences from which no one can dissuade her. She distrusts mental health professionals and psychiatric treatment in general. When we talked further about the impact it has made on her life, her anger increased. Her account takes us into the depth of her anger and despair over the differential treatment consumers are offered:

I’m not willing to give the system so much kind of like rope you know what I mean, like I’m not willing to give the system that much kind of credit you know, I’m sick of seeing [consumers] dismissed, I’m sick of seeing people treated like their genetically different,
I'm sick of seeing people puffed up you know with the power from the taxpayers money, and the taxpayers include everybody, consumers are taxpayers … and these they, these people they puff themselves up and they, they flaunt, it’s like a leech, you know that is being filled with blood right, but the blood isn’t theirs, it’s somebody else’s blood right, and and I see these kind of people and I see them as shuffling pieces of paper around and they’re not really accomplishing anything except providing them and people like them with jobs, and so I mean I don’t have any respect for them at all, I, I don’t see any signs that they want to change.

Mary’s anger is directed at people who she perceives as using consumers in order to be more powerful without a desire to alter the power structure. A number of participants experienced a difference in power between themselves and professionals which they attributed to the disparity in status and prestige.

Power Differential on All Consumer Committees

An alternative view of the power differential was offered by Mark and Jory who participate on all consumer committees. Mark has experienced a power differential between himself and other consumer participants. Mark believes that the only thing that has really changed with the advent of all consumer committees is the face of the oppressor from mental health professional to consumer participant:

Presently the psychiatric system is the people, the doctors and stuff are the leaders or whatever, the sheep herders, and the mental patients are the sheep, with this other [committee], it’s like a consumer has taken the professionals place, rather than a few ranging horse tribe or whatever, horse herd, …it’s like a mental patient has taken the
In relation to Mark's experiences with other consumers and power, it was interesting to look at Jory's stories regarding her all consumer committee. In relation to the other consumers on her board she said that they were really supportive of one another. "Our chairperson, not only gives us information, she also gives a heavy dose of humour about herself and we're all learning from her, I do some help as well, like when I participate, I try to give them, and it's kind of like we form a bond and like, we trust in each other." Despite the support Jory receives from the chairperson, there is a sense that there might be a lot of power asserted by the chairperson on the rest of the committee. "We have a good Chairperson, she does most of the work, I try to help her, she's kind of esoterical, she wants it to be a one-woman show and all the rest of the people can like glorify her." Jory seems to recognize the power differential but in her eyes it is not that problematic. The experience of inequality does not appear to be as much of an issue for Jory as other participants in the study.

Power Differential in Favour of Consumers

Another idea on the inequality between mental health professionals and consumers was offered by Julie and Gerry. They sometimes felt that they had more power on boards and committees to sway decisions because of their consumer status. Gerry reported that consumers on his board serve as final validators for the agenda and decisions. Gerry stated that, "the way the power is structured, everybody is saying nowadays, 'oh we have to listen to consumers,' so people feel when I speak that they should hold their tongue and listen to what I say, now maybe sometimes they should, sometimes maybe they shouldn't, maybe
what I’m saying is quite ridiculous.” In Gerry’s view the inequality exists in that he has more of a say in decisions than non-consumers. When asked to expand on what he would see as an ideal balance of power he offered the following. "It’s never good when one person talks too much and starts influencing the ideas too much of the other people ... there should be a lot of interplay and a lot of contribution made by everybody before consensus is arrived at."

Julie’s experiences on boards and committees were similar to Gerry’s in regards to inequality and power differential. When discussing the issue of equality on her board Julie said:

It’s hard to say that I’m less or more powerful, in some respects it’s like I move my little finger and the world stops because I am the consumer, you know, I am God, and this scares me just as much you know having to bang on the table to be heard, it’s like I’m just another person at this table and I have a certain perspective but everybody’s got a perspective ... rather than me being more important or less important than anyone else. Despite the fact that the inequality in power is in her favour, Julie still finds this disturbing. A further example of the inequality on the board in favour of Julie’s status was provided.

"Sometimes I feel like in a way, [consumers] get a lot of credit for showing [up] and [consumers] get a lot of credit for contributing, ... and I think that everybody should get that kind of credit." Although the majority of consumers reported a power differential in favour of the professionals, both Julie and Gerry felt that they sometimes had more power to affect decisions because of their status as consumers.

In summary it appears that the participants experienced inequality or a power differential
between themselves and non-consumers. It was theorized by the participants that the differential continues because of the training of mental health professionals and that change within organizations can take a long time. The inequality was experienced in terms of differential treatment at board level in terms of recognition and being heard with non-consumers having the upper hand. It was also experienced in terms of differences in status, occupation, and attitudes held towards them that made them feel inferior. The differences in power was not experienced overtly for one participant, rather, in a more discreet manner. Furthermore, a couple of consumers provided their experiences with power differentials on all consumer committees. Alternately, some participants felt that they had more power to sway decisions because of their status of consumers on boards and committees. Overall, the participants experienced inequality in their interactions on boards and committees. The overriding emotions of this differential was that of anger, resentment, and distrust of professionals.

Subtheme: The Experience of Being Assertive for Female Participants

"Of course he feels he can control women better but he knows he can't control me and that's why it's the administrator, he's having such a difficulty with me." - Chris

Among the female participants a subtheme emerged dealing with the experience of being assertive on boards and committees. The female participants struggled with assertiveness which they linked to their socialization as women and their expectations from others. For some the perception of "not rocking the boat" was reiterated through gender norms for women and through belittling by others when they did speak out. Despite the pressure to meet certain standards for behaviour, the participants were assertive or learned to be. Jory
was the only female participant that did not share in this common experience.

Julie experienced a subtle form of pressure from other female members on her board not to rock the boat and follow the norms for female behaviour. Julie perceives this expectation as stemming from generational differences between her and the other female board members. Julie says that, "there are gender issues but in a sense they're generational issues, I think that I feel more with the somewhat older women on the board rather than the men." Julie also feels that her own socialization as a woman may prevent her from speaking up at times. In a conversation with some of the women on the board Julie experienced a sense that she was to not be assertive and rock the boat like a "good woman should":

There is this one woman on the board though that said something about how nice all the women were on the board right now and that and that you know there have been some people on the board, I'm just trying to get the story straight, it was very vague the way it was told to me nobody was trying to you know step on anybody else's toes but there had been other female board members in the past who were I guess real hell raisers in one way or another, and it sounds like possible unreasonably so but I really didn't like the way their unreasonableness had something to do with them being women you know and especially women it was really kind of odd you know.... I tend to have a very cynical sort of sense of humour about [that] will come out and gets my point across but there are other times when I shut up for the sake of keeping some kind of peace and, I think that is something that is conditioned into me, I'm not saying that a man doesn't feel it too on some level but I feel like it is conditioned into me as part of being woman, that I'm nice, yeah that I'm going to be a nice person and, or I'm going to be a pleasant person and
well liked, actually as I get older that’s less and less important to me you know, it’s sort
of like I’m here to get the job done and, and I get a lot of comments about that from
people that I, that I comes across really strong.

Although Julie experiences internal and external pressures to keep the peace, she feels this
doesn’t dissuade her from always speaking up or using her humour to make her point. When
asked whether or not she feels there is a lot of pressure on her to keep the peace Julie said:
Well there is now I mean I had never heard that verbalized before and it was at a social
gathering it wasn’t at a board meeting that this was said but it was just sort of admiringly
how nice we all were by another woman on the board and that, that has really set off
alarms in my head and as far as I’m concerned when we start meeting again ... it’s riot
girl you know.

Julie has experienced the pressure to comply with sex role norms for women, however, she
doesn’t agree with them and will pay closer attention to this issue while participating. Overall
Julie believes she has learned to be assertive on her board which ensures that she will be
heard. “I’ve learned just to talk over people, that’s a very uncomfortable thing to do but I
think it helps in meetings anyway if you’ve got something to say just keep talking because
you do get talked over otherwise.”

Another female participant was similar to Julie in terms of her own learning in being
assertive and not always pleasing others. Chris states that she is aware of her own
transformation on boards and committees from the traditional behaviour expected of women
to a place where she feels comfortable in speaking up:

I used to be Polly-Anna you know, everything positive, I still am, I mean I still try to
bring out a positive before I give somebody something to grow on you know type thing
and I don’t hesitate to do that, to bring out a positive and then say but however this
comment or whatever, but I’m not Miss Polly-Anna anymore, I, because it’s just,
there’s too much, I don’t know the term, but it’s a nice term for it, just too much bull
shit you know that gets in there and people just get carried away with it so I’m pretty up
front about what I say and what I do, well most people seem to accept it:

Chris feels that her own expectations for behaviour made it hard for her to speak out,
however, assertiveness has been something she has learned through her experiences on
boards and committees despite negative repercussions. For example, she said, “like I spoke
to some people in Victoria one time … and they didn’t like what I was saying so one fellow
said to me, ‘Chris, isn’t your husband taking care of you,’ meaning in bed.” Furthermore,
Chris believes that the Administrator she works with on her board has a tough time dealing
with her because she will not take on a passive role and let him control her. In talking about
the Administrator she says, “of course he feels he can control women better but he knows he
can’t control me and that’s why it’s the administrator, he’s having such a difficulty with
me.” Although there was a time when Chris felt that she took a peacekeeper role on boards
and committees, she feels she has grown more assertive and can challenge anyone she may
need to.

Mary also experiences the expectations from others to be passive and conform to the
traditional sex role stereotypes for women. Nonetheless, like Julie and Chris, Mary is
uncomfortable with this and speaks out despite this expectation:

I still think that there is that fear for me, around being assertive around men … I don’t
think I feel comfortable and I don't think they feel comfortable and, and also that you
know, yeah, it's like I'm supposed to be sweety and that goes along with being docile
psych patient, right and I'm supposed to be as sweet as I can be and I suppose too, like
boost their ego, and I'm supposed to you know, like, I can't be bothered with that right,
I cannot be bothered with that ... but I mean with these men they're used so used to you
know seeing women, and especially women psych patients, but women in general like,
you know, be their secretaries and be their reminders and be their tidy uppers and be
their, and and I mean, I'm very clear when I speak, I think they're not used to that kind
of speech from a woman, either, they're more comfortable with women who kind of like
do the securest thing.

Even though Mary feels she is assertive around men despite her own discomfort, she also
believes that the men on the committee have difficulty with this type of behaviour. Mary
states that, "the man in the psychiatric establishment, right, defined how they thought a
woman should be you know, they defined me as how they thought a woman should be, and I
still feel that ... that's what they do." Mary has experienced certain expectations on her
because of her status of female on boards and committees.

Nancy also experienced the expectation to fulfill a passive role in dealing with a male
chairperson on one of her committees. In discussing the following incident, Nancy attributes
his harsh behaviour towards her as stemming from the perceived threat to his authority when
she speaks up:

He gets brutally angry and of course he's traditionally fouled mouthed and he, just in the
[agency] he drove all the women away, they just couldn't cope with him anymore, I
mean I was at the point where I was going down the street just crying continually

towards the end of the [agency], .... but it wasn’t me who decided that he just couldn’t
deal with women but then you looked at the fact that four females were driven off that
committee because of his verbal abuse and the whole thing that he was doing, where he
and I broke [was] everything was fine so long as we supported him but then when I
would question and when I insisted that when needed a constitution or bylaws and this
sort of thing and working on those, he didn’t like it, and when I said that if we’re going
to have an office it should be open and he should be in attendance if he’s going to be the
boss, he didn’t like that, that he was going to be the employee, he liked that even less....

One issue also at that meeting was where a woman had nominated herself to run for the
board but [the Chairperson] decided that she couldn’t because there was no proxy vote
and I said, “what the hell does proxy voting have to do with it,” well I didn’t say it that
way, I said, “this is not proxy voting,” I said, “she’s running in absentia, she has
applied and she should be able to get votes the same as anybody else,” I said, “the fact
that because she’s not here she stands very little chance of getting on the board and it has
nothing to do with it, you have not said that people must appear at the board meeting in
order to be elected,” and blah blah blah and so then people started looking at this and
considering and he turns around and says “well you fucked things up again Nancy,” and
that’s kind of attitude if it’s not his way its the highway unfortunately.

In summary, the female participants experienced pressure from internal and external
sources to fulfil gender role norms for women, in particular, passiveness and peacekeeping.
Despite this expectation the female participants were assertive or had learned to be assertive
The Experience of Positive Outcomes

Among the accounts of the participants emerged common experiences involving positive outcomes from board and committee work. The participants' involvement on boards and committees was a vehicle for positive experiences such as friendship, empowerment, and increased self esteem.

The Experience of Friendship

"I met a lot of really fine people you know, some of them are not so fine but I still like them because of what's underneath all their pain and anguish you know, I've met some really fine people and made some really good friends." - Mark

A common theme that emerged among the accounts of the participants was the experience of friendship. Board and committee work provided the opportunity to meet new people and feel part of a group. The participants also experienced a sense of connection or bonding with others, both professionals and consumers. Furthermore, the experience of friendship also involved feelings such as support, belonging, respect, and being cared about. The support and caring from others created positive feelings for the participants. A couple of the participants also reported that friendships gave them an opportunity to learn. Overall, the experience of friendships was a positive one for all of the participants.

Part of the experience of friendship involved the opportunity to meet new people. In fact, one of the things that Mark said he would miss most was "being friends with the people that I'm already friends with and meeting new people." Chris also states that she would miss "the friendships that I've developed." When asked to provide an example of this friendship
she said, “well I don’t know, associates and friendships I guess that I’ve met at the [organization] and people I’ve [met] regionally and people I’ve met through committees and yeah regionally.” For Chris friendship and meeting new people is really networking in her eyes. “Well I shouldn’t say just friendship I guess I should say networking you know, meet the people that you’ve worked with and cause it’s a big part of it.” An example of her networking involved a brief she wrote written in response to a policy that she didn’t agree with. The networking brought about increased support from other people who recognized and agreed with her concern:

I wrote a brief on, if they were talking about having, having these advisory councils of consumers to mental health services and in the smaller rural areas like there isn’t the population to draw from, so I wrote the brief, I don’t know, 10 or 12 pages it was a shorter one, so I sent that there and I sent that all over the province, and anyway they had already being thinking about putting this thing on the back burner, so there was the networking that people, when they saw it in black and white they saw how ridiculous the whole concept you know it was just something the government sort of and, what happened was the government and the consumer caucus got together and they [decided] heh, this is okay, we were going to do this, and there was no vision like you know, there was no goals, no objectives, how to achieve this and this is where I bring in the training of consumers and I was just, I was just, I was just furious, that you know they were going to try to do this and the rural areas like I pointed out the statistics of the population ... it just didn’t jive at all, so I sent this and I fired this off, right to so many people, so that’s part of networking and I got a lot of response from it.

Chris and Mark’s experiences with friendship includes meeting new people and developing a connection with them.
Friendship also entailed the feeling of connecting with others or forming bonds for many of the participants. Jory stated, "I think I would miss almost the comradeship it's like a bond I guess." In relating the sense of enjoyment she derives from her friendships she said, "sometimes we're just like little kids, just let ourselves go and just enjoy each other, laughing and joking." It was also clear in Gerry's experiences as to the bond he has been able to form with one of the other people on the board. Gerry said:

I would say overall, it's been a pretty positive you know, I've made a very good friend through my experience there, and you know, we always have a phone call for about three hours after the meeting and we say, "well ah, what did you think of that? Did we do anything positive today?" And "no, I don't think we did much today," "no I didn't think we did much either." It it's just the human contact that I enjoy, you know, I guess if I had a goal, it would be that, that I would make more friends like [Traci] and get to know more people and really have that that bonding friendship that we have, you know that for me, is everything, I think friends, are you know I think you can never have enough good friends.

Julie echoed Gerry's experiences of feeling connected with another consumer on the board. In talking about her relationship she said:

It's been a very interesting experience for sure and it's very strange in a way that of all the people that I should clique with on the board it should be the other consumer because, but there's more there than just our certainly our experience of mental illness in common, he's he's done a lot of things that I always wanted to and he's just an interesting person and we spent a lot of time together, and I guess it's an added dimension that we can be so encouraging for each other, I don't know where I'd be without him ... but I wouldn't say that that's because he's a consumer.
Both Jim and Mary also reported a sense of connection with people they had met through the boards and committees. In Jim’s case, the experience of friendship with a woman he met through his committee provided him with a strong desire to develop more relationships:

She came over and picked me up and we went out to another, and we just started talking and then it was like wow, and I got to know her and it was funny in how it evolved and stuff and I started talking with her and she wasn’t even a I guess, a youth or anything, it was funny, I was starting to get to know her and it was really neat how it all evolved … not your intimate like sexual, but intimate in the sense of I have a bond with this person … people that she referred me to talk to, gave me some phone numbers that, one of them was the [council] and I called them and I guess it was no longer in existence but then I started feeling heh I need some more you know, I want to get on to another thing.

Similarly, Mary experienced connecting with some of the professionals on her committee which was a unique situation for her given her past distrust of the psychiatric system. Mary has been able to develop a sense of connection with male and female members both of whom have professional position:

Well I’m starting to be able to determine people who genuinely like me, to people who don’t right, I’m starting to let it you know…. like [a professional woman] okay, I’m starting to like her right as an individual as somebody I think has you know, you know professional hang-ups like she doesn’t think about a lot of things but that’s why I’m there is to make her think about a lot of things right, but as a person I think, I could like her you know.

The new relationships Mary has formed with a couple of professionals on her committees have allowed her to explore new ways of relating. Mary’s experiences of friendship with professionals have allowed her to rethink old views of relating. For example, with one
professional she feels she can relate on a personal level and joke around:

Like [a professional man] okay, is somebody that I thought was almost from the very start that I would, I could talk with him as person right, so after a year and a half, [a professional woman.... and that with a few people, two people that I’ve met that I can, like I can joke with right, at least or something you know something like that right, a human thing, whereas with the other people it’s just like no.

On the whole, Jory, Gerry, Julie, Jim, and Mary share a common experience of friendship involving a sense of connection or bond with other people on boards and committees.

Friendship was also experienced by a few of the participants as a sense of support or caring from other people on boards and committees. Both Mark and Gerry have felt a sense of caring from women they have been in contact with through boards and committees. Mark stated:

I’ve met and made a lot of friends through the people that I meet on the boards ... one lady up in [city], she’s a really good friend of mine, you know I can phone her and she’s really a good person and really ... concerned about me and I’m concerned about her and you now, like I’ve said I’ve met a lot of really fine people but they got their problems too you know.

In describing his relationship with this woman he says, she “allows me to phone her collect, you know I could phone her once a day if I wanted, you know she’s pretty well off, her, she’s got a husband and has his you know profitable business and we just talk to each other and support one another.”

Likewise, Gerry experienced the support of friendship from a women on the board who visited her in hospital while he was ill. “When I came into hospital this time I got a very nice card from one of the women who left the board recently, a very nice person ... she just
was very encouraging and said you've got to stay on the board and keep talking and, and that meant a lot to me that our relationship meant a lot to her and that made me feel very good."

For both Gerry and Mark the experience of friendship involves the sense of support and caring from someone through board and committee work:

For Rob the experience of friendship also involves a sense of support as well as being respected:

I would miss the relationships ... because the relationships are important because I've developed some really good relationships with people and like I said not all of them are crazy about me but they respect where I'm coming from, and you know that I've strived for is to be accepted for what I was and you know and, I have that now I've never asked them to like me, but they do accept me for what I am and what I represent.

Rob provided a glimpse into these relationships in discussing his following experience. "It's taken me 10 years to be respected in some circles where I would have never would have been accepted before, right, I would miss that I can go in and talk to anybody on sort a first name basis and not be sort of looked at in a weird way because people talk to me on a first name basis right." Supportive friendships are also experienced by Rob through working along side other consumers on boards and committees. "Once you've been sort of like in a pitched battle for you know, 5 to 10 years, you sit through some pretty tough times with the same group of people, you form bonds and some real solid relationships with people right, and it's that's not there anymore then you're to suffer."

Among the accounts of Julie and Jory also emerged a strong sense of friendship and support from other consumers. In talking about her relationship with another consumers on the board Julie says, "in some sense it was like you and me against the world on the board ... we did get a lot of support from each other." An example of when Julie felt that support
and friendship was at a high society function that her board was hosting where she and the other consumer participant felt somewhat out of place:

I got to tell you a funny story about when I went to the, we were getting ready to go to this fund raising thing and the other consumer member on the board and I were both very concerned about having to walk around and smooze with all these high powered people at this high powered fund raiser thing and, I said, “you know it’s like I don’t know how to deal with the president of [this company], I don’t know what to say to this guy right,” and my friend on the board goes he says, “you go hi, what do you do?” and the guy would go, “oh I’m president of [company],” and my friend would go, “oh, so am I you know!” (laughs) And we just had a good time, yeah we could really screw things up for them but good you know, and it was fun to be able to joke about it and so stupid you know but I guess it’s sort of like it’s okay to call you know for black people to call each other Niger but don’t let a white person do it you know.

Similarly, Jory experiences a sense of comradeship or support from the friendships with some of the other consumers on the committee. Jory states that each of the consumers on her committee take care and look out for each other. “When you are sick you rely on each other more so than on a nurse or a doctor or anything, just together we really watch out for each other, that the well ones look after the sick as they come in and we take over looking after each other almost like a family, only stronger.” For Jory the experience of friendship includes caring and a sense of security. Both Jory and Julie draw support from their relationships with the other consumers on their boards and committees.

For a number of the participants the experience of friendship on boards and committees provided them with an opportunity to learn from others. Nancy reported that she has met many new people who have taught her a lot of different things. “It’s been a good
networking opportunity though because I have learned from other advocates things and some of the people are just great that maybe I can maintain those.” Jory feels the friendships formed on her committee have helped her learn about herself. “I’ve only in the last five years learnt to really laugh at myself and some of the things I’ve done, and some of the things I’ve thought, and I think they taught me to laugh at myself so much.... when we go out for lunch we’re quite boisterous because we like each other.”

In summary, the experiences of the participants on boards and committees revealed a sense of friendship. Each participant experienced friendship in terms of meeting new people, connecting or forming a bond with others, drawing support and caring, or being able to learn from others. The friendships were with both professionals and consumers creating positive emotions for the participants.

The Experience of Empowerment

"As much as we move towards empowerment and, you know, sort of simulation into mainstream culture, I think people have realized that, or started to realize that ... when you think about what we expect from life it’s not anything special or any special treatment, we expect our shot at the brass ring and we need to be able to access the same kind of life that everybody else has." - Rob

A common positive experience of the participants on boards and committees was empowerment. A few of the participants defined empowerment in terms of respect, having control, and opportunities available to them. They also reiterated that empowerment is something one defines for oneself instead of others imposing it on them. In their examples of empowerment the participants noted that they felt powerful in affecting change. The ability to make a contribution and witness positive outcomes was empowering. Others stated that the sense of respect from others, both consumers and non-consumers was empowering. Further
participants experienced empowerment due to the support for their views and experiences from both non-consumer and consumer board and committee members. In addition, a few of the participants discussed that some of the events and activities they had been involved with on their board and committee had been empowering. The experience of empowerment was also linked with equality between professionals and consumers. Overall, the experience of empowerment was a positive outcome of board and committee work.

The participants' definitions of empowerment are interrelated and revolve around the ideas of respect, control, and equality. For example, Gerry felt the respect he gains from his contributions to the board provide him with a sense of empowerment. Rob also defined empowerment for himself and other consumers:

I think being able to vote, well first of all if you take a look from the very beginning since that consultation first became really trendy and politically correct, just being at the table is a victory, being able to actually contribute and then vote and actually make a difference, that that's another victory but actually being able to go beyond that, to to sort of get into the point where you actually get into the community, you know, because people say that you're working with a committee that has to be friendly to you, but actually being able to move from the board room into the community and making some change in the community, that's what empowerment is, what it involved is everybody's idea of equality, it's true equality, it's not [an agency's] version of equality, it's own, it's your own personal version, I mean like I don't think that anybody has the right to set limits for anybody, it's like when you say well I'm going to empower you and I will tell you well you know, as soon as you jump off the bridge and go to hell I’ll tell you that the only one that can empower me is myself and I mean, the supports need to be in place, ... I think it's the old thing
that people with mental illness couldn’t be allowed to make mistakes because it was too, it was too stressful and all that, I think we have to start understanding that people with mental illness need to experience like everybody else does [in] order that they experience what true empowerment is and what real life is all about instead of being sheltered all the time, we’re not frail, we’re just human, I mean I think that that’s something that people have to understand, that nobody defines empowerment better than a mental health consumer themselves, they’ll tell you what their limits are.

Chris and Rob also define empowerment in terms of opportunities that are made available to consumers. Chris states “you can’t empower somebody anyway, I mean you can help people empower themselves and give them employment and give them housing, what I like to say is to create opportunities.” Chris later added, “it is about empowerment, empowerment of the consumer which means, getting available resources and not to be blackmailed by these available resources to do what someone else wants for power, there has to be a venue for the consumer, there must be a venue for the consumers who are, who are getting benefits from an association.” Chris went on to say that the opportunities that have been made available to her have been empowering. By the same token, Rob also sees empowerment as involving opportunities:

It’s about giving people opportunities to involve them in the process, I mean, I think those are traditional ways to regaining self esteem, I mean, they have never been thought of before cause a lot of people apply principles of rehabilitation to people with mental illness and to other people as being totally different, I think when people understand that people with mental illness want the same things that they do, and that the same things apply to them, then I think will have, we’ll be that much further ahead.
Chris defined empowerment in terms of increased opportunities and provided an example:

I guess when I was asked to be on the board I felt empowered, when I was asked to be on the board of [this organization], I guess when I was asked to go to [on business] you know, all these kind of things, they're all sort of a bit of prestige and a little bit of power and you know, they are empowerment, they're all it mean [is] that people respect you too and so you feel empowered by that, I do anyway.

Chris also described empowerment as a process, something that develops over time for each person. "I think empowerment is just a process, I don’t see it as you know all of a sudden I feel empowered, it's just a process, it's a part of me that grows, you know my empowerment because I have the power to, you know talk to convince other people into things too which is part of empowerment, yeah, no I would just call it a process which is just you know slowly developing."

All of the participants provided examples of when they experienced feeling empowered through board and committee work. The examples centered around increased respect, power, opportunities, and support from others. Jim reported that he derives a sense of power as well as pleasure from trying to bring “down to earth” the mental health professionals he deals with. Jim states, “it’s almost like a power trip for me .... belittling, sort of belittling the bureaucrats, I get like a sense of power out of that.” Similarly, when Rob was asked what he would miss most about board and committee work he said, “I would miss the power, the power to be able to change things and make a difference in people’s lives.” Rob also stated that, "feeling powerful is I think in essence part of every human being, I think they need that, I think they need a certain amount of that in their life, it’s a control issue and I mean it’s nice to feel that you have the power to change things, so that’s one [of the] things I
would miss the most." Jim provided an example of how he feels he can derive power from belittling professionals:

Like I was telling you ... about how we've given that form theater workshop and one of the things, one of the situations that came up was I, was like I was acting as a bureaucrat right like this person that does that, like, you know like, "oh nice to meet you," and everything right and they're all arrogant about their position, well one of the situations that comes up in the play that this young girl comes in and I'm like, "Oh nice to see ya, and oh, how's your father doing?" And you know, "Oh I'm glad you got my message and nice to see you," and she walks away and says like, "okay," but yeah, but one of the scene changes is when somebody comes in right and this one girl comes in and what she said is bang on, ... she says, like after I said, you know, I said hello and say all that you know, she says, "but I'd please like it if you know affiliate my personal, talk about my personal affiliation with you at this meeting, thank you," and walks away.

Correspondingly, Rob provided an example of when he felt empowered from making a contribution and from being respected by others. One of the boards Rob sat on was being forced to move the location of one of their facilities due to public pressure. The move would have cost the organization over a quarter of a million dollars, however, Rob's presentation to city council had a powerful impact on the final decision not to move the facility:

I gave a presentation to City Council about, because they wanted to move the [facility], cause there was a lot of neighbourhood reaction to, from [the neighbours], and we already lost the vote to canvass the vote and I did my first presentation in front of a public crowd and what happened, I didn't find out until later, but I walked into a board meeting where basically I had been a very silent voice because it was only my second or third board meeting as a member of the board, and they actually recognized me as the
one who turned around the vote and they still recognize me as the person who turned
around the vote and allowed the [facility] to stay where it was ... because of my
presentation to City Council ... I swung 3 votes out of my personal lobbying campaign
and the fact that I did a very emotional presentation that was very structured but very
emotional and actually I had three city counsellors in tears. You know, like I didn’t
know it at the time, until we found out about the vote the next day, cause the vote was
closed and they they came back with the decision and I didn’t see myself as being part,
you know, the reason why and I walked into a board meeting and they cited it, cited me
for turning it around because they’d lost that, cause it would have cost close to three
hundred thousand dollars to move everything right that’s where, that’s where you
know I felt the most respect.

The notion of respect from others on boards and committees as facilitating empowerment
was echoed in the stories of other participants. For example, Gerry explained:

Well there is one woman who we don’t know each other well, but she is one of the
people I would consider an ally, and she’s worked as a I think a [mental health
professional] ... and a lot of times when I speak of my experience and, and how I see
things and how life is for me and what not, we sort of connect, I look at her and she
looks at me and I just know that there is that understanding and respect there that she
doesn’t feel like I’m saying to her look, you’d better do a better job and get your act
together, because I’m not trying to do that you know, all I’m trying to is say what it’s
like from my point of view and I think she appreciates that and respects what I have to
say and that that gives me a good feeling you know.

The feeling of being respected by others was also evident in Nancy’s experiences which
helped boost her sense of power and control:
In the meeting the other night that I’m not supposed to be at, because they said I’m not supposed to be there but I go to them anyway now, they were discussing an issue and it was issue of governance for the community health councils and regional health boards and one of the things that they were saying was that people had to be nominated and could not self nominate, and the woman said because I feel that flies sort of in the face of grass roots and few people made some comments but of course my little hand shot up right away and when they came when I was acknowledged and I said I have to totally disagree with that I think that self nomination is the very essence of grass roots, I said you know people can be participating and have great skills, like her validation was that there must be one person who can nominate you but that’s not necessarily true, you might be a totally unknown person with wonderful skills but you just haven’t been running in that circle, you’ve been running in some other circle, it’s like when we had our [committee] there was a young fellow who was self nominated for a [position] nobody knew him from Adam but he’s been on the [committee], he works with another [committee], does some stuff with the Ministry of Social Services … I think he’s really clever now … but if he hadn’t self nominated, where would he be, … well anyway after I’d explained this perhaps more articulately than I’ve done here, one fellow to my right said, “oh I agree with Nancy one hundred percent,” … and then the lady who in this meeting who said that she felt it came in the face, she says, “you’ve made a compelling argument there and I want to change my position on that,” wow, geez you know, these are real people and they’ve changed their mind because of something I’ve said, and that was about the first … and that just seems so neat to have somebody actually respect what I was saying.

For Nancy, the fact that other board members listened and changed their views gave her a
sense of respect and empowerment.

For other participants, the experience of empowerment involved feeling strength and support from others on the board, committee, or organization. When Julie first entered boards and committees she felt empowered by the response of other members to the telling of her experiences with mental illness:

Well let’s say initially I felt that strength when I went into a room of people and I said, you know I’ve been struggling with depression for 20 years and I and I, I think one of the things I said when I first met the board was that I thought that with the proper support, dealing with an emotional illness could be [a] profound experience and quite a learning process as well as you know, it didn’t have to wreck your life or that there were you know some things that I felt had made me wise that I had learned from dealing with it, and having that accepted and having you know having said that being welcomed onto the board, was a good feeling you know, that my experience is valid here and as I said that you know that I’m finally going to be able to turn it into something constructive.

By the same token, Gerry reported that when he was listened he felt empowered. Jim also stated that when he feels support from others on the committee he also feels empowered:

Okay, I am presenting a project like say for example, I can present a project you know and I’ll walk in there and I’ll say, “oh blah blah blah”, right, and there will be bureaucrats there but yet the people that I’m working with will be there and I’ll feel more, oh oh, are they going to agree with me, like meaning my, people that I work with cause I don’t care if the bureaucrats, but if I’ve got the backing with the people that I am working with, then I feel more empowered.

Likewise, Mary draws strength from other people on the committee, specifically consumers.
"Oh when I've been on that [committee], ... when there's about three sometimes 4 of us that have gone through the system and there is maybe 3 or 4 professional types and so there, I feel like, like again, other consumers don't always agree with me and I don't always agree with them but I feel that I get strength from having these other people there." Mary stated later that the consumers were a source of strength from which she felt empowered.

In addition to the examples of feeling support from others as a source of empowerment, some of the participants reported that some of the events and activities they had been involved with were empowering. For example, Jory stated that an award her committee was going to present to a supportive organization was an empowering experience. Jory stated, "most of them have just been wonderful to us, there's one that's not but you get that in every crowd, yeah, and I do believe they're giving them award of the year, we're going to give it not to an individual but to the whole group."

Mark discussed an event on his committee which he found empowering. A few of the consumers on the committee were having difficulty understanding the language of the documents so a consultant was hired to help them. With the consultant's help, Mark was able to work his way through the material:

On the [committee], we really worked hard, I wouldn't say we really worked hard but we really put in an effort, we really tried to ah, show that consumers can do it because, and this is how we did it. We worked with one of the [consultants] for the [organization] to develop a stance and issues and help him [educate] us on how to read things and what things meant, and that was really good, that was that was the best, the best experience I had, really ah, you know, if you are prepared and can you know, he didn't really do anything for us really, like he didn't do the work for is, he didn't real the reports for us, we read them all together, or he read it and then we read it or whatever, and if we had
any questions he explained it to us, he showed us the road and then we, we expressed you know well we don't like this, we don't like this, we don't like this and he helped organize what our issues and what we thought would be the umbrella issues and narrow it down and then we made notes, you know brief notes and then we went to the committee you know apparently we did a really good job because [an influential person] was talking to me about you know, “Geez, you know, I heard you did a real good job.”

Mark felt that once given the tools he could be an equally participating member on the committee. He stated, “I, it was really confidence building, I was able to speak out, I was able to disagree, I was able to fight for what I wanted.” He also said, “I came away with a high you know, yeah, I've done something, I've achieved something, I've fulfilled my obligations.”

Both Rob and Chris defined empowerment in terms of equality as well as and opportunities, and provided examples. Rob relayed that he feels equal and subsequently empowered when mental health professionals come to him and complain:

I've had mental health professionals come and talk with me and they say, “well I’m having a bitch of a day and I need to talk about this stuff and somebody just shit all over me.” That’s a nice feeling because, they can go and talk to someone else about that stuff, but they come and talk to me about it, and that’s where you really feel equal, and that’s when somebody feels that they can come dumping all over you, what is even a greater thing is that you have something to offer them that you can make them feel better on a personal level.

Finally, the element of respect and equality was echoed in another of Rob’s statements:

It’s an incredible rush sometimes. I mean but you know, on a personal level, because I do, I have managed to get some things done, I mean I get some
pretty heavy odds sometimes, you know, so the reason that I stay with this ... I mean is because there are those gains and I mean when I go home at the end of the day ... or I you know, I look back at things at the end of the week and say, well you know it was worth it. I mean I was stressed out the first couple of days of the week ... but I said we got something accomplished today, and I keep going because I believe in what I am doing and because with all the anger, with all the pain that I feel, with all the bullshit I have to put up with I realize that there is a healthy respect out there for the things that I do on a personal level and I think that sort of off-shoots onto other consumers too ... so there's more of a respect, it's not give so reluctantly anymore.

The experience of empowerment involved receiving respect from professionals and consumers. There was an increased sense of control as well as an increased amount of opportunities open to participants that was also experienced as empowering. Many of the participants perceive board and committee work as a means to feel empowered however, empowerment is not something done to them, rather, they are an active participant. Empowerment also entailed feeling that they had made a valid contribution to the board or committee that brought about change. In addition, having support from others as well as specific events on boards and committees were also noted as being empowering. Finally, the equal relationship between a consumer and professionals was also empowering. On the whole, the experience of empowerment was a positive outcome for the participants through their involvement on boards and committees.
The Experience of Increased Self Esteem and Confidence

"One of the things I discovered about boards, once I you know, learned that I did have something to offer..." - Rob

Connected with the experiences of empowerment are those of self esteem and confidence. The participants reported that their self esteem and confidence increased over the period of time they have been involved with boards and committees. Their feelings of usefulness, being competent, and involved with meaningful work increased feelings of self worth. Being useful and productive on boards and committees was a favorable experience and led to positive internal changes. Specific examples of events that helped increase their self esteem included speaking up at committee meetings despite the associated risks, being able to persevere on the committees, being useful, and trying new things. Nonetheless, a couple of the participants warned of the dangers of having boards and committees completely define and feed one's self esteem. Both participants called for a balanced approach, however, there were a couple of other participants who recognized that board and committee work was the mainstay of their existence and esteem. In addition, some of the participants reported that they were able to repair old wounds associated with their mental health history due to their involvement. The boards and committees provided an opportunity to regain a sense of agency which had been subsequently eroded by mental illness. Furthermore, they became more accepting of themselves as well as their mental illnesses, and some stated that board and committee membership helped rebuild their lives. Overall, involvement with boards and committees helped increase feelings of self esteem and confidence.

Gerry, Jim, and Nancy all reported that their self esteem and confidence increased because of their involvement. Nancy stated that, "I feel overwhelmed all the time and I don't stop, I feel like I'm dealing by the seat of my pants, I'm feeling more confident now
though.” Julie also related her experiences of increasing confidence, “well initially feeling not so confident in my abilities and then realizing that I can take it on, I mean I work for [a new work government policy] now, you I’m quite involved in that organization and, it has been really nice to sort of start out as a complete idiot but it’s something you know, at the point where I know a lot about it.” Likewise, Rob has gained confidence via his work on boards and committees as seen in the following statement:

Most folks that deal with me now have a healthy respect for me. So most of the time when I go into a meeting, I have that kind of control, that kind of personal control and that kind of respect from people. Ah, the feeling that I get from it, that [it is] for the first time in my life, people are taking me seriously, that I have something to offer the world, that there is something that I do, you know, that I do properly, and that I do, you know [in a] seemingly adequate way.

Comparably, Chris stated that she felt stronger and had developed personally because of her work on boards and committees. “I think these accomplishments, what they have done for me, is you know, along the way, even though I say that you know, my best interests [are] the consumers, it is the consumers, but I have to develop myself along the way and I’m sure that [name of a few boards and a trip she went on], all these things has done this for me.” Moreover, Julie experienced an increase in esteem and confidence because of her involvement on boards and committees. In talking about her self confidence she said:

Well I think it’s something that comes out I think, I’m getting better as I get a little comfortable with everyone, and cause I think I get a little bit more comfortable with my role on the board which changes a bit, well what that role is exactly, but, the fact for example that I’ve come out and said that I would like to be on the [branch of the board] next year I think sort of shows that there’s more here than just a consumer you know,
and the fact that I'm sort of becoming the boards expert on [government policy] I think it's kind of cool you know, and that the Executive Director thank God is someone who you know, she's helped me to cultivate this knowledge and now she refers people to me if you got a question about it you go to her, and that's nice that I've been given this expertise outside of my sad story I guess you know, and that is making me feel more confident, but again it comes from being treated like a person.

Overall, a number of participants experienced a growth in their levels of self esteem and confidence.

Further participants experienced an increase in their feelings of self worth as expressed in terms of feeling useful, meaningful work, and feeling competent. For example, Gerry's board and committee work offers him an opportunity to feel productive again:

I have been able to connect with more people yeah, we're not really close friends or anything, but we have developed a sort of mutual respect, the kind of respect which hopefully people enjoy in the workplace, the respect which comes from appreciating the fact that we're all doing our job and we are all trying our best, that was something I enjoyed when I held a job and that is something I miss keenly being unemployed and being away from work, yeah, the aspect of professionalism of doing a job, doing your best job and seeing that it's good and having other people recognize that you are competent, you know, that's that is a wonderful feeling, that's a wonderful feeling.

Jory also feels her esteem and feeling of usefulness increased over the period of time she has been involved:

When I lost my job I didn't want to quit, I didn't want to stop, I was in a routine, I guess it was a treadmill I was on, a work treadmill; I did some great things with my [work] we were on television several times and we did, I was a super [job title], I think,
but I lost my confidence, over seeing my [job] I lost, I lost a lot and it [is] getting back, functioning properly at a level I feel good about myself again.”

In comparison, Jim also felt an increased sense of confidence and usefulness due to his involvement:

Well the best way to describe it is you know, you have something like I guess, if somebody wants kids, they, and when they finally get it, it’s like heh, right on and then they see their kid accomplish their dream and it’s like my son’s done it, or you know, or whatever, and they see it happening, the parents feel really good about it and I guess that’s the way I felt like really good about what I was doing and what I [was] saying and useful like you know, what I was saying meant something cause other people around had been through what I was going through.

Similarly, Mark stated that when he was first asked to join the board he felt a boost in his feelings of usefulness. “It made me feel like Geez, somebody thinks I can do something.”

Furthermore, Rob’s self esteem has increased because he feels his role is meaningful:

There has been tremendous recognition and respect and the fact, and the fact that you know I get called to do a lot of stuff so I mean that’s another part of it you have to be really careful that it doesn’t go to your head you know but I mean, you know as far as, what it has done for me personally with my self esteem because you know I’m coming from a place where you weren’t allowed to have any self esteem and basically beat into the ground all the time, so that the fact that I’ve finally found something, you know, I’m going to be [this age in this month], I was able to find something I was good at it where I could actually care about people and you know, make a difference and that’s the pay off too, and I’m not on welfare anymore I mean I don’t make a lot of money but I’m better off than about 99% of the other people that I represent so I mean there’s been
benefits for me personally too.

Rob feels productive, and like Jim and Mark, it has given him additional esteem and meaning in his life.

Further examples of increased self esteem and confidence included the ability to speak up at board and committee meetings. For both Julie and Chris, the new sense of self emerged after they risked speaking out at the meetings. In Julie's case, her board had been discussing an action plan for some time, however she thought it was a poor plan:

When we were asked individually for our response to this action plan [that] was going to be presented at this meeting, and I felt like a voice in the wilderness when I said, "I think this whole thing is garbage," and then when I went into the meeting and discovered that was the general consensus, it was a good feeling you know, not that I had lobbied, it wasn't like I had anything to do with that, but I wasn't dog shit after all, a feeling that everybody had.

Related to Julie, Chris also spoke out at a board meeting which help to increase her self esteem:

I'm also comfortable in speaking my mind where this is only something that has come in the last year or so, that I'm comfortable, before I'd be very uncomfortable and I wouldn't speak out a lot, as much as I so now, but I'm very comfortable, I don't have a problem with it .... I think it's all a matter of self esteem and just the different things that happened that I worked on and probably, [this hospital board] has made a tremendous difference.

In a like manner, Nancy feels good about herself for being able to make it through all of the meetings and sees the rewards of involvement as being internal. "I don't know how to describe it, I don't want to belie everything I've said by saying that it can be ever so
rewarding but the rewards that you get from it are not necessarily those bestowed upon you by others but the internal satisfaction that you get even from just hanging in and making it to another meeting sometimes.” Gerry shares with Nancy the internal satisfaction and positive self esteem from board work. He states:

It’s good experience for me to serve on this, it’s it’s like in a way it’s like an intellectual exercise or something, it’s sort of hard to explain, but you, it isn’t like getting together and chatting with your friends, you are there for sort of a business purpose and I enjoy that you know, I enjoy the professional aspect of it, the fact that I’m that I’m sitting down with professionals and that we are finding common ground to meet on, that for me is very satisfying.

When asked if this example meant his needs for self esteem were being met Gerry said, “right, yeah, when you’ve been out of work for awhile and you’ve been in hospital a number of times, you’re self esteem kind of takes a beating, you know, you get older and you start to figure am I good for anything anymore?”

Jim offered another example of increasing esteem through board and committee work. He said he felt good about himself when he started something new that consumers may not have been involved with. He also related his experience of getting business cards as boosting his esteem:

Well yesterday I went in and to this place, this business card place, and I don’t even, oh I don’t make like a wage off of my work right but I still do a lot of my work right but I still do a lot of this work so I figured I always have to give out my phone number so I might as well get some cards printed up so, but it felt really neat to have this like saying and stuff like that to come up with it and everything you know, and it was like it felt really meaningful you know.
The Danger in Board and Committees Defining Self Esteem

An interesting idea emerged in regards to self esteem from both Julie and Chris. Chris warned that there is a danger for boards and committees to become the only source of esteem for consumers who participate. In this situation it could be harmful as one’s sense of self becomes interwoven with everything on the board or committee. For example, if something negative occurs then the person’s sense of self will suffer. Nancy reported that her sense of self is intertwined with board and committee work and experiences the swings from good to bad according to the progress of the committee. As Chris states, "you have to have a balance in your life of everything, not just spiritually or a need for success or whatever, there has to be a balance." Julie also echoed the need for balance, “it’s like there’s this, I think maybe the danger is, it happens in any committee where you sort of you know, hang around with people who are, the only connection you have with them really is one particular facet of your life, you focus exclusively on that facet of your life, or almost exclusively.” Chris asserts that without balance then the boards and committees can become the lifeline of a consumer and this poses some difficulties. “I think sometimes that that’s their lifeline, you know they’re bored and that’s where they’re going to, and if they lost that, you know say working on, then they would lose their identity, but I’m sort of scattered all over.” In discussing how Chris was able to find a balance, she said:

It is part of the process, yes, it is, I think that when people get on boards and start feeling, if they do start feeling good about what they do, some of them don’t some of them do, you know because if the process is not there for them too, they don’t have the type of people who encourage that process for them, but for the people who do, you know, I can see it as something that they hang onto because they haven’t got anything else.
Julie also warns that an individual’s experience of mental illness could become the most important part of their presence on the board which could be problematic:

I think that as a consumer sitting in an organization like that, it’s important to share your experience because it’s really, as much as we talked about how you don’t want to single yourself out, if you’re going to go into an organization as a consumer rep you have to be prepared to reveal yourself at that level it’s sort of it is part of what you are there for, I wish it was part of what everybody was there for but but, certainly it’s part of the job to tell that sad story and, that’s hard to do sometimes so I think you’ve got to be brave on that level and I think you have to have a strong sense of yourself but at the same time you don’t get sucked into that you know, that that’s the only thing that’s important about you, about your experience there.

Similarly, two other participants provided insight as to how board and committee work can become problematic in taking over one identity. For example, Mark is contemplating leaving board and committee work because he feels he has lost a sense of himself because of his involvement. “Lost, about my ideas, my philosophy’s, my beliefs.” He later added, “I got to do a lot more thinking about myself and what I want and what I think is best in order to go forward or else get swallowed up, chewed up in the screws, and spit out.”

Nonetheless, Mark finds it hard to leave because it has become a big part of his life, “I’ll probably end up going to another meetings and all that crap ‘cause I mean, it’s part of my mainstay …. I don’t know how to quit, it’s like ah, it’s like, it’s just like smoking I guess, I mean you know once you start and you do it for so long you don’t know what it is like not doing it right.” Likewise, Nancy reports that everything in her life revolves around board and committee work which is painful at times. For example, when asked what she would
miss about her work she said, “purpose, meaning, identity, everything would be missing, I would have to find something else because there’s no me, there’s only what I do is what I am, other than that there’s no me, so I would have to have something, I would have to get deeply involved in something else.” Nancy agreed that board and committee work is integral in defining herself and went on to say, “which is why when something goes wrong, it destroys me, not just discourages or something it’s because I am in that, I need to find another focus, to balance this one.” Both Nancy and Mark recognize the difficulties in having board and committee work play such a big part of their life and self esteem.

Increase in Self Esteem and Confidence and its Relationship to Mental Illness

Further insight into the increase in self esteem through boards and committees revolved around mental illness itself. A few participants discussed mental illness in terms of losing control and subsequently confidence and self esteem. The boards and committees enabled some of the participants to regain some self esteem that had been eroded due to mental illness. As Julie states:

I think anybody who’s experienced a mental illness and you know, managed to come out the other side, especially that, you know, that that you managed somehow to get over the worst of it, is very different than somebody who’s never been through anything like that, I think that pertains in a way to anyone’s who’s never really experienced a serious problem in their [life], you know it just humbles you, it does humble you, it’s so while there are many personality differences you know between people, I still think there’s common experience of having something take over your life that you really don’t have control over.

Jory, Julie, and Jim share the common experience of coming to an acceptance or understanding of their mental illness thereby increasing their self esteem. Julie said:
It’s been a very interesting journey for me in exploring my own relationship to this illness that I have, I guess a lot of what I react to I think are my own insecurities and feeling about it you know, I think I do to a certain extent project things onto other people own fears and insecurities and things like that, but at the same time it’s by, interacting with those people and challenging these things that I get behind it whether I get beyond it in myself or I’m change other people’s point of view, help them get beyond it, there is a change process, so I’d say it’s something you do for yourself, it’s not something you do for anybody else .... this has been a very interesting experience in coming to terms with depression and it was really, in this period of time since I became involved with the organization, not just with the board, that I’ve begun to accept my own illness rather than thinking of it as a personal failing, I really think of it as more, it’s a condition you know, it’s just something I have to deal with and slowly I’m getting away from my own judgements about it.

Jory echoes Julie’s sentiments and states that she has gradually come to accept her illness and herself:

It changed my attitude, my whole self concept, this board and, and comfortable with people.... I was always ashamed of my disease, very ashamed and, kind of paranoid, almost to the point of hysteria ... of people finding out that I was a mental patient, I see a lot of people are used to it because they’ve been in touch with each other, they’ve accepted it, I never accepted mine, I fought it, and I went back to work all the time and I don’t know what people around me must have thought because sometimes I was not really fit.

Julie also stated that having other people around to talk to about mental illness made a difference in her acceptance of the illness and eventually of herself:
By talking to other people I start to know what the common experience is and that helps me in dealing with myself because you know, I realize I'm not alone, but it really is an illness, it's not, it's not just something in my head, and it helps me to get some perspective to carry on with the, life in general, or whatever, but being on the board has been a real challenge to that ... in some ways I felt like I was you know, going to be stuck being a sick person and then slowly I think I'm being able to grow out of that.

Jim feels he can turn his experiences with mental illness into something positive, for himself and for others:

What I really strongly believe is that there is three points in like how we live right, on how that we as society live ... and how I believe that we should run our lives and basically it says one is awareness of the situation, two is acceptance of what is going on, and three is, three action.... action to create change or to keep it the same, so basically that's like what I get out of it you know, not playing the victim anymore, I get into the role of trying to change the part that was affected in my life so I try and, instead of looking at the negative of it, I try and change it into a positive, it's still recognizing that it was there but still trying to make it better for others and myself and by doing that it makes it better for myself cause I'm helping others in the process, helping to change the process ... and it empowers by old situation that was once and it takes away knowing that it's not what it was like, it is what it was but I don't have to stay in it.

A few of the participants stated that board and committee work not only builds their self esteem, but also helps them to rebuild their lives. According to Gerry, “it’s helped me on the road to reintegration being involved in this board.” Rob adds:
I mean working, I mean, you must be familiar with what mental illness does to people, I mean employment is one of the last things on your mind, you know when you are down and out and there is no where else to go, and I mean, while I realize that employment is not important to all consumers, it might not be possible, I mean if I couldn’t work if I didn’t have this focus in my life I’d be in [the psychiatric hospital] all the time because that’s the kind of person I am so what it’s basically done is sort of restored my reason for being alive.

Julie shared a similar belief:

It’s rebuilding it’s like okay, what is left of my life now, and it only been in the last couple of years that I have thought about things in terms of how so I live with this illness rather how do I avoid it, or how do I, how do I not think about it and there’s still times when I’d rather not think about when I’m healthy but I [am] coming against more, becoming more at peace with the idea that it’s not something that’s going to go away, if I’m lucky it will be under control ... [it] has helped me to build that life.

Some of the participants share the common experience of increasing esteem through acceptance of their illness. Board and committee work allowed them to be with others and reintegrate into the community.

In summary, the participants shared a common experience of increasing self esteem as part of their work on boards and committee. Increased self esteem was expressed as feeling more productive and having a meaningful role to play. The self esteem and confidence stemmed from incidents such as speaking up against issues on the board, persevering on the committees, being useful, and trying new things. Some of the participants warned about the potential of involvement on boards and committees to completely define one’s sense of self
and the need for balance. Two of the other participants shared their experiences with this idea and the difficulties of having their esteem woven into board and committee work. Finally, a few of the participants discussed how mental illness can erode self confidence and esteem, but that board and committee work was a vehicle for healing this part of their life and helped them to accept their illness and themself. Other participants said it helped rebuild their life. Overall, the participants experienced an increase in self esteem and confidence as part of their involvement on boards and committees.

On the whole, the participants shared in common three positive experiences through board and committee work. The three positive outcomes were, the experience of friendship and connecting with others, the experience of empowerment, and the experience of increased self esteem and confidence.

The Experience of Disempowerment

"It's sort of like, makes you feel like a sheep you know, you're just going and somebody else is directing you, so yeah, it's, it's disempowering." - Mark

A common experience among the participants that was negative in nature was disempowerment. Some participants described disempowerment as a lack of support from their environment, including consumers and non-consumers. Others felt disempowered when there were barriers in front of opportunities, being bulldozed by other participants, feeling overwhelmed to represent all the views of consumers, and specific tasks on boards and committees. At the core of the experiences of disempowerment was powerlessness or a decreased amount of power. Certain participants also experienced disempowerment when they and other consumers were devalued or invalidated. In addition, the inequity in financial resources was also reported as being disempowering. Overall, the experience of disempowerment was a common one shared by the participants and can be contrasted to the
experiences of empowerment discussed prior. In reviewing the experiences and definitions of empowerment offered by each participant, the experiences of disempowerment appear to be natural opposites. However, disempowerment is part of the process of board and committee work rather than an outcome of it.

A few participants described the experience of disempowerment as a lack of support from their environment. Each participant defined support in their own terms however a lack of it usually brought feelings of disempowerment. For example, from time to time, Jim said he may feel disempowered at meetings and he may leave the board room. “Sometimes I can for through a meeting and I feel really disempowered and I walk out in the middle of the meeting for an hour and then come back right, and then it’s like oh okay, I feel better right.” When asked to provide an example of when he experienced disempowerment, Jim offered the following, “just when people don’t accept what I’m ah, I guess when I was writing out that proposal a couple, back in [the winter] and it was shot down right.” In another part of the interview Jim described the time he presented the proposal which takes a deeper look into his experience of disempowerment:

One example, specific example I can think of is, [the winter months] I was at the [committee meeting] it was like I said earlier I am the only mental health person and as the direct result of that I walk into a meeting and I sometimes I say, social services, the only people involved in this and, I spoke up and I, no, first of all I brought in a proposal and they didn’t go for it right, it was, I guess I didn’t and then I felt really dumb because I didn’t, or not dumb isn’t the right word, didn’t I just didn’t feel like you can’t really express it properly so…. so I started talking with people and then they gave me some suggestions and but then that feeling of like he needed to so he won’t, we won’t talk to him anymore, like he needed help so we won’t talk to him anymore, and
then later on, when I broke down, I broke down in a meeting and I said, "heh look is mental health represented here?" They all looked at me, they said, "ohh," they were supportive right, like everybody was supportive and they said, "yeah it is," and everything right, and "you are a pioneer right now so if course you are going to feel like that."

When Jim feels inadequate and a lack of support from others he also feels disempowered.

Chris experiences disempowerment when opportunities are blocked off to her which is congruent with her statement that empowerment is that of having opportunities. "When opportunities have been blocked off, I think the most disempowering is when it goes on for a long period of time and there doesn't seem to be an end on sight." Jory is similar to Chris in that her opportunity to stay on the committee is being threatened and this is disempowering to her. When asked to provide an example of when she felt disempowered she said, "when I was asked to resign, (laughs) no, I wasn't asked to resign, it was suggested that I might want to resign." Jory decided to take a leave of absence instead of resigning because she still wants to keep this opportunity open to her. "I'm going to take a leave of absence, rather than a resignation.... I find it quite disturbing then the [past negative event on the committee], but you see, I, if I took a three month leave of absence that would make it to [this time] and then the real work on the [next event] would begin ... that's when I could be involved again." For both Chris and Jory, lack of support in terms of blocked opportunities are experienced as disempowerment.

Mark said that he feels disempowered when he is bulldozed by other people on boards and committees:

It's sort of like, makes you feel like a sheep you know, you're just going and somebody else is directing you, so yeah, it's, it's disempowering, you know, can I give an
example? ... For instance this, this committee you know, my, my lover came to the came to the meeting for the first time and then I phoned her up that night and I was a little bit drunk and she was a little but drunk and she started giving me shit about, I forget what point I was trying to make, she started giving me shit about this, the you know, the following this one guy blindly and my allegiance and, so that really made me think you know, Geez, you know how much should I believe everybody you know, how much should I, it just reconfirmed that you've got to be able to think for yourself, you, it's really dangerous when you follow somebody blindly .... I want to be effective, I just feel like one of the sheep being flocked.

Mark experiences disempowerment in terms of being overpowered by others instead of pursuing his own thought and desires.

Another participant experiences disempowerment in terms of feeling like she has too much pressure on her to make decisions for the organization because of her consumer status. Julie sometimes feels that her views carry more weight in comparison to other members because she is the consumer and represents the views of all consumers. When Julie feels this type of pressure she feels overwhelmed and states that she “can’t function”:

The reason I would say that is again, I guess it has to do with my view of you know some people, might find that a [positive] experience, you know, to have people listen that intensively, but my fear is that nobody’s got a monopoly on the truth and if I'm looked at as some kind of ultimate spokesperson, you know, where I am carrying the weight of the decisions and how will they affect consumers, ah, it paralyzes me you know, I can’t think, I can’t make a good judgement, I can’t even make a good judgement for myself because I’m you know, overwhelmed by what that decisions going to carry, you know if I really felt that, that I was the only person who was being polled or that I
was somehow was supposed to be polling all other consumers involved to make this decision I'd feel very uncomfortable because I think it's got to be shared, the board in a sense to me should be the voice of the members of the organization, it shouldn't be the other way around, and that's why I feel uncomfortable.

At the core of Julie's disempowerment are the feelings of fear, helplessness, and lack of power. The dichotomy is interesting, the more power she is given in terms of making decisions for the organization, the more she feels disempowered or unable to function.

Mark's experiences are further linked with the idea that certain responsibilities on boards and committees are disempowering. He discussed that he felt disempowered when he was unable to fulfil the responsibilities of his role as consumer representative because he could not understand the language in the documents:

I really try and pay attention, but I, what am I feeling, what am I experiencing, like a loss or waste actually, cause you know I get paid a certain amount of money to participate on some boards and I felt guilty not you know, I look at Dr. whoever, they are right in there, they've read all the material, they understand it all, and they’re interacting, or they’re writing notes down or whatever, I can’t even understand the crap they read, they've given me to read, some of it, some I read through fully, some I just breeze through some I try and get into … and if I’m not getting it by the third or fourth paragraph, I just say well there's no point.

Subsequently, it was when Mark was able to get some support for understanding the documents that he reported feeling empowered in terms of his contribution to the board.

In addition to the lack of support that the participants experienced as disempowering, a number of them reported that when consumers are devalued in one way or another, it is disempowering. For example, Rob brought to light the fact that when some consumers share
their personal experiences of mental illness with their board or committee they are sometimes shut down. Rob believes that when consumers are not listened to for their personal experiences it threatens their role on the board or committee. When asked how he feels when somebody doesn’t want to hear his personal story of mental illness, he offered the following:

Well, it makes you, it wakes up all the old anger in you, because that’s the way you’ve been treated all your life I mean mental health system has always treated consumers like that as if they had no voice I mean and when somebody shuts you down because, they belittle your experience, I mean understand that a lot of consumers only have that that place to come from I mean their experience with the system has been based on their own personal experience, I mean it shouldn’t be devalued because I mean that experience is what’s going to break their portion of work of that committee, I mean that’s what they’ve been asked to that committee and you devalue it and you shut them down at the very beginning because it’s an emotional issue for them, then how are they going to be able to contribute.... the most valid thing that we have to bring to the table is our experience of the mental health system, I mean if you’re going to consult somebody of something don’t narrow the terms of that consultation or you know what are we going to bring to the table?

The invalidation of consumers’ experience is disempowering in Rob’s eyes, which is congruent with his beliefs that empowerment includes respect and being able to contribute.

Similarly, Julie believes that it is disempowering and invalidating when consumers are seen as only being able to contribute their experience with mental illness rather than skills they might possess:

This came up on one of the meetings where I was talking about how we were...
going to have, strike little sub-committees to discuss various policy issues ... 
that we should try to get a consumer involvement with each one you know,
and the argument that I got back, was that, not all of the issues in the
organization necessarily pertain or needed consumer involvement, and I sort of
choked on that, I didn’t say it although I sort of wished I had to some extent
but I sort of felt like saying oh alright you know, I forgot people who have
fundraising skills don’t get mentally ill you know ... it’s like the idea that
somehow being a consumer that’s your skill that you bring to the board you
know it’s like you don’t have any other skills ... and you know I think there
could be lots of ways for consumers to be involved in the organization without
necessarily having to wear their consumer hat.

Julie later added, “it’s an invalidating experience in the sense that what they are saying is
well you’re only valid as a sick person, you’re not valid as a healthy person here, your
experiences as a healthy person don’t count anymore than ... mine do in a sense, and and,
you know, that’s obviously makes you feel fairly crummy.”

A further participant also felt that some of the ways she had seen consumers treated had
been disempowering to them. Mary agreed that disempowerment meant someone’s power
was being taken away and/or they were not listened to. “It was the [board], because been
talking for over a year about how to make this place a safe place for consumer to come onto
this board, [a] couple of people show up and they’re silenced, you know, was really really
angry with that, I, there have been times when people have treated what I have said as
ridiculous and stuff like that, that’s made me really angry.” She also said that it was
disempowering for consumers to have to enter board and committee meetings with obviously
less resources for clothing and finances in relation to the professionals they would have to
work with:

Like I get paid for example to go to these meetings right and [other consumers] don't, and like there's difference for people because I have a job I can walk in there and feel like I'm roughly dressed, like not in the same style but like I can hold my own but if somebody doesn't have a job, and they walk in and they're on welfare and they have shoes are really awful and they don’t have them, the expensive haircut or whatever, I don’t know why they did it, I wouldn’t even be around that kind of scene.

In summary, the participants experience disempowerment in a number of ways. The lack of support on the board, blocked opportunities, as well as the pressure and responsibilities that come with being a consumer representative are all disempowering. Furthermore, the feeling of powerlessness and being helpless is at the core of disempowerment. The devaluing and invalidation of consumers experiences as well as their contributions at board level was seen as disempowering. As expected, the experiences of disempowerment can be paralleled to the participants' experiences of empowerment.

The Experience of Frustration

"I mean I don’t even know where to start because I find it so frustrating you know." - Mary

Another common negative experience among the participants was that of frustration in dealing with elements of board and committee work. There were a number of areas to which the participants attributed their frustration such as the slow process of boards in producing tangible results. The board process was also frustrating because it was sometimes demeaning and difficult. Furthermore, some participants experienced frustration in dealing with the group dynamics on the board usually in the area of getting along with others. At times some of the participants found it frustrating to work with non-consumers as well as with consumers. The arguments between themself, other consumers, non-consumers, and the
personality conflicts were all reported as frustrating. In addition, frustration was also linked with mental illness and it’s subsequent negative impact on board and committee work. A couple of the participants were frustrated with their own illness while another with the whole realm mental health problems. Moreover, two participants were frustrated because of unmet expectations in gaining employment through board and committee work.

A number of participants reported that they experienced frustration with the slow process of boards and committees. Most participants wanted results and action to occur at a quicker pace than it did on their board or committee and experienced frustration when it didn’t. For example, Julie states:

Well, initially I was very frustrated, I thought, you know, there’s a 2-year term for this board and at the end of 2 years we will have accomplished nothing, and you know what will that say about my contribution you know part of me was saying you know the first consumer members in the board you’d like to leave your footprints in the sand so to speak you know, that, that, you did something constructive there, I don’t know that I gave the energy to go on another term, but after about the first 8 or 9 months I started to realize that things were moving but it’s really slow motion, you know and that, in a way life is like that when you’re dealing with organizations and when you’re dealing with large groups of people, that you just sort of have to let it go, let it be that slow and, just you know take what little gains you can get out [of] it, it’s sort of like watching a glacier melt in a way, when I’m feeling really negative about it.

In conjunction with Julie, Rob shares a level of frustration with the slow board process. Rob attributes some of the frustration to his own impatience to see things change in the mental health field:

One of my problems is that I am not a process person, I have never been ... I mean
they can stick me in an office and give me all kinds of fancy titles and paper but ... I’m more comfortable on the street that I am in doing administrative stuff and you, I don’t have a real good taste for this stuff, I am in a hurry a lot of the times because people that know me will tell you that I am not an administrator ... and I have this vision and that it is a little bit ahead of everybody else’s vision, but you know, some committees I don’t do too well on because I get tired of stalling and you know, this stuff, nothing really is happening.

Mark provided some specifics on why the process is so slow and frustrating:

It’s all the bureaucratic red tape, that’s why it takes so long is you know, there’s so many people there and you got to convince everybody, and then you got to have an action and then you know you got to decide on a motion, which usually involved an action, which, and then you got to find the people to do the action and, and you got to keep on the people to do the action because it’s all a volunteer board or whatever ... and you got to have group consensus on all the decisions and it’s hard, because it’s all in the name of participatory democracy.... decisions have to be made, and more decisions [on] it, once you’ve made that decision more decisions have to be made and no work really gets done you know, say there, the decision is, or the motion on the table is to put the cup over here, okay, and you discuss it and make a motion and then, then decide who’s having the action and then when, they’re going to do it, and all that stuff and by the next meeting, you’re lucky if the cups still there, or if it’s moved over here.

Furthermore, Jory stated, “I get things mixed up and I don’t always go through the Chair to get things down and it’s not, it’s not good. Proper channels in the mental health system take forever to get paperwork done, they’ve got to do something about that.” Julie echoed this view and said:
It just seems like something about the way organizations are set up, it’s like we all have these traditional formats that we seem to have to follow where, you know you don’t talk about something unless it’s on the agenda, or you don’t you don’t you know if it doesn’t fit into the format of a report then it doesn’t get included in the report or it’s like who set up these rules anyway?

Although the participants suggest change in the mental health system could be faster, Rob realizes it could never be fast enough for him. “I mean we’re not all the way there yet but certainly I think that we’re doing a lot better, we’ve made progress, I mean they’ll never, never be you know, quick enough for me because I’m very impatient.” Nevertheless, Mark asserts that he is frustrated because of his perception that boards are only talking about changes instead of taking action on them:

If you are going to build a fortress you can only talk about it for so long or if you are going to build a bridge you can only plan it for so long and that’s all, that’s all I see this, you know, they want [to] bridge the gap between the consumer and non-consumer right and all I see this committee work and board work doing is talking about it, not actually digging the foundations at each end and putting up the structure.

In the end Mark suggests, “if all I’m going to do is get frustrated and down on myself or end up getting drunk or whatever, you know personally, it’s not worth the participation you know and that’s why I am questioning it all, the whole thing you know.”

In association with the frustration experienced due to the slow process on boards and committees, there were also additional frustrations mentioned in dealing with other elements of the process. For example, Julie was frustrated by the fact she had little support from board members at times, not having access to the board minutes, and the general enormity of the tasks at hand. Julie reports:
You wouldn’t invite a dog to this thing so you know, we’ve got to do something to jazz them up to make them more real more relevant or something like that, I’ve heard that from staff members too, I don’t know what the board does, it’s like I want to get the board minutes but I don’t you know, it’s like they I never seem to have access to them, this kind of thing just frustrates me to no end and I guess it’s a constant struggle between you know, will I snap under the level of frustrations and start screaming at everybody at a meeting one night, and I’m wondering why I bother even holding myself back from that maybe it would a very good thing to completely flip out and just scare everybody to death (laughs), but you know on the other hand do I really want to invest a lot of energy in this, it really is just something that’s too big.

Other participants reported similar frustrations, for example, in summing up his experiences Mark said it was, “fulfilling frustrations.” Furthermore, Mary stated:

Like it’s very difficult me knowing that I should be there as part of my job to represent people and hopefully to be sort of, open the door so that other people can come onto it but at the same time feeling put down and feeling frustrated about the process, you know? So that’s why I do it as minimally as I can because I know that I should be doing it for other people but at the same time I find personally so frustrating that I can tolerate only a little bit of it in my life.

Similarly, Mark added, "you know you only hit your head against the wall so many times that, before it feels good to stop. I guess you got to hit it a lot of times before it feels good to stop." Mark stated that his frustration level increases because he does not know as much about boards and committees that he feels he should:

It’s really frustrating, it’s really hard to do especially when you’re not, I mean I’ve been doing this for a long time, longer than I have been doing a lot of other things, and I still
don't know the exact process, I don't know if I'm to Chair a meeting, I don't know what the, like I have a better idea now than I did 6 months ago or 8 months ago, so it takes a lot of exposure to you know, I guess I could read books, or I could whatever but it still won't sink in.

Likewise, Rob added that the whole process is just really frustrating, "there's an awful lot of frustration and pain and anger, I mean like I tell you sometimes at the end of the at I wouldn't want to live with me, because I mean, I might not say anything at the time but it builds up in me." On the whole a number of the participants experience frustration with the board process, whether it be slow, demeaning, or not completely understood.

**Frustration with Group Dynamics**

Some participants also experienced frustration with group dynamics such as personality conflicts and working alongside others. The frustration usually stemmed from conflict and interactions with other board and committee members. For example, Nancy states, "one of the frustrating things is you have a good idea and somebody else makes out like it's all their idea and you kind of wonder what happened." Furthermore, Chris experiences frustration because she doesn't believe there is enough expertise on the board to evaluate programs and policies for people with a mental illness:

I find it very frustrating that in mental health, in [this organization] anyway, that we don't have the expertise on the boards, that we don't have clinical backgrounds, we don't have legal backgrounds, that you need to run something, you know our administrator tried to devise a vocational program which is highly inappropriate for consumers, his initial aim was to make [the organization] self sufficient, and he in the process, he would be exploiting consumers.

She later added in discussing her administrator:
Well it’s frustrating because his goals are not the goals of the consumer, for the consumer, he has his own goals, his own agenda, and that’s not what we’re here for, that’s not [what this organization] is there for, so instead of putting your efforts into a good vocational service which we could have had by now, we’re putting our efforts into stopping him from doing you know, whatever it is he wants.

By the same token, Nancy is also frustrated because she feels her committee members also let her down. She experienced frustration when only a handful of the members showed up for a meeting:

We decided to have our consumer [committee] meeting [here] once a month, and to get people more involved with committee work hoping that, that [it] would be a manner of developing it, and in the entire, only one committee meeting happened that was scheduled and that was just 2 people showed up, myself and the other sort of dependable person who’s usually there, and so at the meeting the other day I talked to them about it and I was pretty blunt and a matter of fact I’ve written sort of an apology for it because I feel that I didn’t have to treat them that way and I was a little bit unreasonable, but it was a case of saying well look you guys, you’re not pulling your weight and I can only do so much, the staff person and I cannot do it all, we’ve got to get this together you know and I get frustrated by people who only come because there’s $25.00 involved for them to come a meeting, and yet at the same time if their experience is valuable, it’s valuable, and certainly some people can come to a meeting 2 or 3 times if they’re getting paid and then you just pray that they’ll catch the vision and that they’re there because they care, but then they’re taking and dealing with their illness as in taking such risks which is hard and I get frustrated sometimes, and I just I don’t feel that I have that right to get that frustrated with people who I’m recognizing and saying to other people you
know we’ve not had the opportunities and this sort of thing, but then I get frustrated, and I think it’s because, I’m just overworked, I’m doing a lot I don’t know when to say no.

Similarly, Jory experienced frustration watching 2 committee members disagree with one another:

At one time I remember one of the directors, I won’t say which one, came in to talk to us, she witnessed a disagreement between 2 members of our group, she watched, she sat and listened, they had been arguing and verbally attacking each other for the last half hour of the meeting, we called a break, and, of course, I went down for my cigarette, so did everyone else, came back and they were still at it, through the break, I didn’t want to take sides, but the Director was there watching, she looked from person to person, they did not reach an agreement, or that a win/win situation or anything, they were both losers in it, and to see 2, they’re both good people, they’ve got their own priorities and one is responsible for [this project], and the other is directly responsible for the, a lot of things in the mental health getting done.... I sat and listened and then we got the meeting back going again, we didn’t leave it, I can’t remember what happened after that, I just remember these people and I thought to myself at the time, will we just shout at each other when we’re both in it for the same purpose, like marriages sometimes, destroy each other, when that’s not our real purpose.

Comparably, Nancy is also frustrated by the abuse between consumer members, particularly as it can be directed at herself. Nancy reports:

I think part of the frustration now is, I have struggled, I have taken a lot of abuse from other consumers, verbal abuse, they’ve shown me considerable disrespect at meetings where the chair has just sat by and let this happen.... you’re getting kicked in the teeth by the professionals and stabbed in the back by consumers and that can be frustrating,
that's why you always keep saying why am I doing this, what matters, fortunately I have a couple of people who are very supportive.

Both Jory and Nancy experience frustration when members on the committee abuse each other or themselves.

An additional area of frustration for some of the participants in dealing with others on the board, was that of expectations. Chris feels frustrated by the expectations of others which she thinks are unfair or inappropriate:

I guess my frustration comes from the expectations of other people you know that then well, I've made no bones about the [government and an organization] have not met their responsibility, and I guess that that feeling has come more and more from that paper I talked about that I wrote ... the whole thing was so ludicrous, I looked when I read it, it when the, the ADM and the [person from the government] met and they decided they were going to do this and then they called a meeting 3 weeks later everybody flew down, for what, I said you're kidding no, this is what we're going to do, I said you're kidding me, no, this is what's going to happen, I said how, where, what where's the rational? Well the ADM's really excited, I couldn't believe how stupid the government could be, how stupid [the organization] could be.

Chris is frustrated by the expectations and actions of some of the people she comes into contact with on boards and committees.

Experience of Frustration with Mental Illness

Both Julie and Gerry experienced frustration in relation to their own mental illness and participating on boards and committees. Julie said:

Well I guess it's not so much that everybody else is looking at me and that I get frustrated, I get frustrated knowing that this is just the way it is for me you know, it's
just kind of a, God here we go again you know, just when things were going okay and, I find that very hard I guess to deal with all the emotional issues as well as trying to be, some kind of conduit or some kind of a clarifier of mental health issues and how they affect consumers generally, I find it difficult to be objective about mental health issues when I’m sick because I just hate the whole situation so much.

Gerry on the other hand is frustrated with the enormity of the issue of mental illness and rehabilitation. “It is frustrating, but I think that the frustration, is to do with the, the whole nature of the problem, the problem of mental illness and the problem of knowing how to treat mental illness and how to provide proper facilities for people who have mental illness, these are like horrendous problems, you know.” Gerry states that he doesn’t get frustrated with other board members but again, with the whole area of mental health:

I really don’t feel that frustrated with like the people I serve on the board with but I feel frustrated with the whole mental health realm, I went through a thing a few months ago where I said where I start saying I’m going to create some distance between myself and the whole mental health system cause it’s such a downer, you know, and here I am here in hospital again and the problem won’t go away, it’s with me, I’ve got it and, I guess it’s just it’s a real struggle to make the best of what is often a pretty gloomy kind of situation you know, not just for myself, but for a lot of people.

On the whole, both Julie and Gerry experience frustration in terms of their mental illness and its impact and implications for their participation on boards and committees.

Frustration Due to a Lack of Employment Opportunities

A final area Mark and Jim experienced frustration was that of not gaining employment through their board and committee work. Mark entered board and committee work with the expectation that it could lead to employment and is frustrated because this need has not been
Ever since I got into this crap and started getting paid for it, I said well I want to get, before I get a job, before I make an opportunity for myself I want to make other people opportunities, and that way it will make it look like that I deserve a job right, but it's not happening. I'm getting really sick of this, I mean I've been trying to buy this car, I owe a bunch of money.

Jim is also frustrated and disappointed because he has applied for various jobs and despite his work experience with boards and committees, he has been turned down:

There's always this gnawing feeling like I don't get paid yet, yeah, that's, I guess that the one time that I can remember me not feeling, feeling on top of the world but then it all came crashing down, I guess that's the best way to describe it, I had this feeling like yeah, I'm going to get the job because I've had all this experience and all these other youth don't know what they're talking about you know and all this right, and then I felt that I really had the job you know, and the 2 people that I said straight to their face that they weren't going to get it got it, you know it was like, is there a message here or what you know.

Both Mark and Jim feel frustrated by their lack of employment offers through board and committee work.

In summary, a common experience among the participants on boards and committees was frustration. Some participants were frustrated with the slow process of boards and committees in achieving results, the protocol for passing motions and producing tangible results. A further area of frustration involved interacting with other members in the group, both consumers and non-consumers, as well as dealing with conflict, abuse, and inappropriate expectations of them. Other participants experienced frustration in relation to
their illness and involvement on boards and committees as the issues in the mental health field are overwhelming. Furthermore, a couple of the participants were frustrated because they expected to gain employment through board and committee work however, this need was not fulfilled. On the whole the participants shared a common experience of frustration as part of their involvement on boards and committees.

The Experience of Feeling Separate or Different

“I feel sort of like I’m not part of that world you know, not part of that culture in a way and so it accentuates that sense of otherness that I have.” - Julie

The theme of separateness or being different from others emerged from the participants’ experiences on boards and committees. The experience of feeling separate or different can be described as a sense of otherness or feeling alienated from others. Some participants felt set apart from the board or committee as a whole because of their socio-economic and consumer status as well as due to the communication in the meetings. They believed different rules were applied to them or they were viewed as being genetically different. Furthermore, several of the participants felt separated from other consumers for a variety of reasons such as past disagreements or their “elite” role on boards and committees. Subsequently, a few participants experienced feelings of isolation and loneliness because of their sense of separateness or being different. Moreover, a number of the participants experienced the threat of separation from consumers by being co-opted by the mental health system and provided examples of this experience.

The subtheme embedded within this theme is the experience of intimidation when first joining boards and committees and then gradually settling in.

Some of the participants described themselves as being separate or different from other people on the board or committee. According to Gerry, “I think that the way that they
system was started in the beginning, we were designated as consumers so we were distinct, a
distinct part of the board, a different colour from the rest of the people on the board because
we came on as consumers.... we had a different role, yeah, right from the start.” Julie
attributed the sense of otherness to stereotypes regarding consumers and that having
consumers on boards and committees is still a new phenomena. “I keep coming back to this,
I think the more consumers get involved, the longer we stay involved, the more normal it
will be, it’s not normal yet, and so it comes with all of the stereotypes stuff and batting it
around bit I still think it’s a good thing.”

Many of the participants reported that they felt separate or different in comparison to the
other members on their board or committee. There was often an imaginary barrier or line
between themselves and other members. Gerry states that he feels different from others
although he is unsure if other people see him this way. “Sometimes it can be like a self
imposed barrier you know, I don’t know if other people see me as different but I see myself
as different.” Mary added, “like there’s people want to put up barriers for me well that’s
their problem right, I don’t even have to deal with them but that’s what I think happened....
and I have not even [a] real interest now in doing whatever, going behind, trying to get
behind that and get to the person.” Mary later suggested that the barrier between herself and
other professionals can be compared to the Berlin Wall. “I’m not used to dealing with
professionals, and so at first dealt people to people right, person to person, but then they in
the end put up, I think is what happened, they put up the Berlin Wall you see because I’m
there, they’re the professional right.”

Further participants felt their experience of otherness was due to class differences
between themselves and other professional members on the board. Julie asserts:

I’m not part of that world you know, not part of that culture in a way, and so it
accentuates that sense of otherness that I have and I think it’s the legacy of this sort of, philanthropic class or whatever you know, that it was considered that if you were of a certain professional level that you would do good for the community as well as I certainly don’t have anything against that but it just creates this strange kind of situation where you know, I, again it makes it that much harder to validate who I am, what am I doing at this table, I’m sitting here with a vice president of a company and a lawyer, and a director of a school and all of these people and I’m struggling to finish my university and I’ve been off and on medication and it seems like my life you know, it’s a challenge to get out of bed in the morning sometimes and I feel like I just cannot relate to this sort of super achiever role in front of me, it just makes me feel really, I don’t feel inadequate I just feel I’m on another planet, it’s like I cannot I just cannot relate to this stuff…. it separates me I think, in a way I’ve created that for myself.

Likewise, Mark’s financial inequity in comparison to other members makes him feel separate or distinct. “Sometimes these professionals talk about going shopping or going out for lunch or you know, shit, you know the last time I was on vacation was for the [trip], I don’t have to pay for it … I mean I haven’t [been] out of the country since 1982, you know these professionals talk about going to Tahiti and Palm Springs.” Like Julie, Mark also feels separate of distinct. Nonetheless, despite Julie’s experiences of being different, there are also feelings of pride with this otherness, “it’s like I’m [from the] school of hard knocks kind of thing or whatever and so and so, you know, certain pride in that too but I do feel that sense of otherness, I didn’t know how much other people experience it too, but it’s very real.”

For both Mark and Julie the experience of otherness involves the recognition of the disparity in status as well as finances between themselves and other board members.

Other participants felt separated due to the differences in communication between
themselves and other professionals members. Julie and Rob both commented that it was as if non-consumers speak a different language than themselves. According to Rob, “it’s just incredible the kind of stuff that gets thrown at you right, you know, I mean it’s like they speak another language.” Continuing along these line Julie states:

Sometimes I feel like I’m speaking another [language] than these people and it’s like, well we’re all speaking a different language, I would like to, you know to take the example of getting more consumers involved somehow, it’s like I’ve talked about this with other board members and I can see them trying to understand what I am saying and it’s not, I haven’t figured out how to bring that issue home to people you know, it’s a non-issue to them, oh I don’t know well, we’ll invite people to meetings or something, you know, I just feel like that’s not going to do it you know.

Both Rob and Julie experience a separation due to communication issues with non-consumer board member.

The experience of being separate or different was echoed in the accounts of some of the participants in terms of having different rules, and being treated as “genetically different.” Rob and Mark assert that because consumers have a mental illness, different expectations of them exist. In comparing consumers to professionals, Rob says, there are “different worlds, different rules and you know, yeah ... it’s the old saying about having to be twice as good to be as good.” Moreover, Mark states, “just different, and from my being different you’re alienated, and you’re prejudiced against and you know, because you are different .... if there were more, if more of us [consumers] around, you know and us and them, if there were more of us around, things would be easier for me to speak.” Both Mark and Rob feel that different rules apply to them because of their consumer status.

In a like manner, Mary experiences a sense of otherness or separation from board
members because she believes they view her as being genetically different due to her mental illness:

I don’t really hold with the biological model, chemical model insanity or whatever you know, and so sometimes I’m in that meeting, these meetings, and that’s the impression I get from people, that they think, they believe in the biological model, chemical model, that, that I’m genetically I’m different from them, you know, and so if you know, like it’s always like I always got that, they are waiting for me to kind of like lose it and become this mad woman you know, and because I don’t hold, that’s part of the reason that they have problems thinking that I can be as whatever.

Furthermore, Mary believes that the reason that the professionals create this barrier or separateness is to justify their position of dominance over her:

So I think that if they because they have this biological model in their mind, that you know this is completely, separates and that’s what they want, they need that separation because I mean if it was proved to them that I was just like them, only you know I had a really intense you know, manifestations of whatever you know are prevalent that they had I mean wouldn’t be able, how could they continue to treat people the way that they do if they had that outlook.

Mary feels separated from non-consumers because according to the professionals she possesses differences in her biochemical make-up which justifies their superior position.

Experience of Separateness from Other Consumers

A number of the participants also reported that they experienced isolation or separateness from other consumers as part of their experiences on boards and committees. For Mark and Nancy the separation from other consumers is a result of arguments and fights which were distressing to them. For example, Mark’s said his fights with other consumers has left him
isolated and lonely. "I wouldn't say that I am really alone cause I have a lot of people I can
talk to, well, I had a lot of people I could [talk] to about it, (pause), it's really, I guess it is
lonely, I guess it is." Likewise, Nancy feels alienated from other consumers which is
upsetting for her:

I am kind of alienated from the, from other consumers in an odd way, there's about 10
people who are perceived to be the leaders in the province, if 10, some people cut it to
9, so, it can be difficult when they reject you, curse at you, swear at you, talk at you,
about you behind your back and generally cause havoc that way, and that has happened
starting with [these people] those are the primary ones in my life who, with a lot of them
I have a problem, but the others, you know [these 2 people] take it upon themselves to
let me know that I'm not wanted.

The experience of separation from other consumers has been difficult and Nancy whispered
in a wounded voice:

It is sometimes right out of control and it's like total isolation, and I keep thinking what
am I doing wrong, and then of course somebody like [a mental health professional] will
say you're not doing anything wrong, but then I say well that's your opinion.... and
sometimes you say what good is it if a stranger says I'm okay when my family [or
consumers] says I'm terrible, and that's kind of the situation I've been doing my job in.

It is apparent that both Nancy and Mark experience a sense of separation from other
consumers due to the disagreements that have occurred.

Alternatively, Jule experiences a disconnection from consumers because of her "elite"
position on the board. Before joining the board Julie was a volunteer for the organization and
had a lot of connection with consumers. Her position as board member has put her in an elite
position thereby separating her from the consumers in the organization:
Well in some ways like when I talk to other consumers about being on the board it’s a little bit embarrassing in a way, it’s sort of like, it’s almost like crossing a line between us and them or something like that, it’s just it’s just very, because the organization is so new at involving consumers in a meaningful level, there aren’t a lot of people in the organization to share experiences with and stuff like that.

Julie feels her position separates her from other consumers, she said, “I feel like I’m sort of one of the royal family or something like that, it’s very strange.” She added:

It’s like there is more of a separation all of a sudden, and you know I suppose partly that’s just because you know, the volunteer hours that I have are spent on the board you know, maybe if I wasn’t on the board I would feel more connected to the organization in that way but I think any consumer on the board is going to feel that disconnection, just because of the fact there aren’t very many consumers on the board.

In short, Julie, Nancy, and Mark experience a sense of separateness from other consumers because of past disagreements and their elite position on the board.

In addition, a number of the participants felt lonely along with the experience of separation. For example, Jim is the only mental health representative on his committee which can cause him to feel lonely at times. He stated that it was a lonely experience, “especially when I am dealing [with committees] that involve mental health that I am representing right.” The intensity of his experience of isolation led him to leave the room at one meeting. Chris echoed a similar experience and said, “I guess what you need most of the time is just somebody to talk to, you know, and because so many times you think we’ll you’re all alone, what do you do about a situation. Moreover, Rob states that he experiences being separate and subsequently lonely because people are used to having him help with their problems, yet, he has few people he can turn to when he has a problem:
I mean I think you know one of the things that I’ve discovered especially of late is that, you know people have [expectations] of you they see you as always being strong and yet you know when I need somebody, it’s hard for me to find anybody that will listen to me because they have this expectation that your whole world is just hunky dory that you never had a bad day, and there have been times, especially since I quit drinking where I get really depressed, I mean I can’t find anybody to talk to because they’re so used to me solving their problems for them right, it’s like I’ve sort of managed to walk up the mountain and I’m standing up there by myself and like nobody will ever believe that I could be weak or anything right and I mean that’s probably because I’ve created that sort of image because I am ... I’m tired of being alone you know, I mean it’s they just told me it’s go to bed, tomorrow you’ll feel better, you know, it’s like you’re not allowed to be human anymore I mean you’ve sort of worked your way out of the sewer and them all of a sudden you know you never have another bad day, believe me it’s not like that, I think anybody will tell you that, I mean you know we have bad days like anybody else.

Experience of Separation and its Relationship to Co-optation

In relation to the experience of separation from consumers was the concept of co-optation as offered by a few participants. According to the participants a consumer who has been co-opted is someone that has become separated from the people they were commissioned to represent. Co-optation occurs because of the consumers immersion and acceptance of the culture of mental health professionals and mental health system through board and committee work. The danger in being co-opted is that the consumer becomes distanced from the people they are representing and more like those they originally wished to change. As Rob puts forward, “I think the danger if you don’t keep in touch and remember what you’re bottom line is again because you could, you can [be] co-opted. For example, in relating her
experiences Mary said:

I was turning into this kind of person too who would always be asking about money right, money, and I say myself do that today like ... and that's like within my right but I don't want to become like these other people from these agencies and sort of pick up my ears when money is mentioned because that's one of the things I totally despise about them you know ... not becoming like the system.

The consequences of being co-opted are intense for the participants, it involves pressure and fear of being separated from the people they represent. As Rob added:

I mean and I don't want to come across as being corny here, but I think that it's real easy to buy the start trip and to become like this mental health system if you allow it to be will create a superstar out of you, you know, the thing that keeps me grounded, I think about the people that are walking on this end of town, in the downtown east side that have no services and the mentally ill are walking around talking to themselves, those are the people I want to represent and I remember what it is like for them and that's why I don't, my head hasn't gotten you know, out of size, because these are the people that matter the most, individuals don't matter.

Mary echoed this view and revealed that she tries to remain as separate from the mental health professionals and mental health system out of fear of becoming disassociated from consumers:

Well, always aware, I'm aware [of] holding myself away from these people because when, for one reason I don't want to become co-opted by the system, I don't want to become a creation of these professionals, that they can blow them up when it suits them and deflate when it doesn't suit them right? I have to have some integrity, I have to remember what I'm there for is to represent people who are not there right? So I find it
very difficult to relate even at personal level, because all the time I’m conscious of the fact that I could be co-opted, I mean you know, that horrifies me, and so, it’s like almost like if they say it’s a nice day outside I mean I would have to check out the window and I, and if I say, I agreed with them it would be like I’m being co-opted here right?.... And also that, that because I’m there representing other consumers that I can, I can of have to, I have to have integrity for them, I have to be able to speak.

Similarly, Nancy has been accused of being co-opted and is aware of how this can distance her from consumers and have them lose faith in her:

I’ve been accused of having being co-opted and brainwashed ... like we’ve been accused of wanting to set up our own bureaucracy and I keep thinking well maybe ours will be a friendlier bureaucracy, and co-optation, I think that the potential is there and that’s why we have to be ever on-guard, and although I don’t use the word a lot, it’s there in the back of my mind and so I think the important thing for me is to try and be sure that people that I care about still have faith in me, and I think that’s all you can do.

Like Nancy, Mary feels the need to deal with the threat of co-optation and does so by distrusting the non-consumers which serves the purpose of distancing her from them. “I keep my distance and part of the reason I keep my distance is because of my distrust of them, but also to protect myself .... that I would be made, that I was their creature, for me it’s a mind of very us versus them situation .... now I draw the line.” Nevertheless, the risk of co-optation is real for Rob and he is astonished at the blatant manner in which it takes place:

Well what I see is that the system works with an elite group of consumers, and it it I mean, and they try to co-opt you, I mean it’s, I mean it’s not even, I mean it’s not even hidden anymore, it’s not even a subtle form, it’s like they actively try, I mean they’ll sit there and lay all kind of trips on you about how great you are and then when you take a
look at where it’s coming from you realize that you know what they’re really doing is trying to put some distance between you and the people that you claim to represent.

For Rob, Mary, and Nancy the threat of co-optation is the threat of separation or disassociation from the people they represent.

Rob and Mary both offered examples of times in which they felt that they were being co-opted or as Rob states, “my base is [a] consumer base and I don’t like being pulled away from it so I resist any attempt to pull me away from it.” In specific, Rob’s involvement with boards and committees puts him into contact with influential people in the government and this has the potential of going to his head:

It’s just that sometimes I’m afraid that I’m losing touch, is that I started moving around with Ministry folks and you know, going into Victoria and you know, get to know [government officials] on a first name basis, and I get round up in that Victoria stuff where I feel like I’m losing touch and that’s, it’s really difficult to come back sometimes and you know, I still do and I realize that it’s a mistake but somebody will call me up sometimes and it’s just one individual and they say I’m having a problem with social services or I’ve got a hotel owner up the street ripping me off for my GAIN check, and it’s really difficult to make the time to accommodate that one person because I’m so busy with everything else but yet I know I’m losing touch with the people that I care about the most.

Similarly, Nancy recalled an incident when she was accepted into the non-consumer circle and experienced this as an attempt to separate her from consumers:

Well what was it somebody said to me at one point, it’s sort of like well you’re okay right, you’re okay, I can talk with you … but these other people like forget it right because you seem to be, it’s like they’re saying to me you know, you seem like sane,
you know rational whatever, I was seeming like that to them, but these other people over there, these other consumers well they're not right, you know, so that, that is really alienating.

On the other hand, Nancy has experienced being accused of being co-opted and involved with the committee for her own good and this has been an isolating experience for her:

I mean I had somebody at a meeting come to me and tell me she wanted to know why, need to know why the professional consumers, did not accept me being on that committee, this was another one I had pushed my way onto, and they resented that, they resented my involvement, there were accusing of me being in a conflict, of trying to feather my own nest and really what I was doing was championing the issues of those people on the committee who did not have the courage to speak for themselves, and so I think, and this is going to sound like I'm whining, it's the truth, I have taken on a lot of people's positions without their support and it's been perceived as these are my issues and that I'm just trying to cause trouble and the unfortunate part is as I sit around those tables, the consumers who agree with me, or have, agree in the hallways, but in these meetings they sit there and hang their heads, and there's no support shown.... Well it's lonely, you feel like you're being crucified by your own.

Nancy, Rob, and Mary were all able to provide examples of the times in which they experienced the threat of separation from consumers.

In summary, the participants experienced a sense of separateness or being different as part of their experiences on boards and committees. They felt separate from both non-consumer board and committee members as well as other consumers. In part the sense of otherness was attributed to socio-economic and consumer status. Others felt there were different forms of communication, rules for each group, and that they were looked on as
being genetically different. There was also a sense of loneliness that accompanied the experience of separation for some of the people. Furthermore, for a number of the participants there was a threat of being separated from the consumer stakeholder group because of co-optation by non-consumers. In short, feeling separate or different was a common experience in the accounts of the participants.

The Experience of Feeling Uncomfortable When First Joining Boards and Committees and Then Gradually Settling In

"When I first started I was nervous but I sort of calmed down a little bit since when I started." - Gerry

A common theme that emerged from the accounts offered by the participants was that of discomfort when first joining boards and committees, however, as time passed they gradually felt more comfortable. The experience of discomfort involved feeling intimidated, fearful, or being out of place. The participants reported three main sources of the discomfort; having to reveal one's consumer status, the power and prestige of others on the board, and the roles and responsibilities afforded them as consumer representative. Jory was the only participant who did not share this experience which could be linked to the all consumer committee she participates on. The reason behind Jory's unique experience could be that the all-consumer board is more supportive and not as foreign as a board with both consumers and non-consumers.

Upon initially entering committee work it was necessary for Mary to reveal herself as a consumer of mental health services which led to a great deal of discomfort for her:

I mean for most people to actually go into a room and say to somebody in a board, I am here from the [consumer organization] right, I'm openly identifying myself, not through, like I might meet you somewhere and start talking and then I would say, oh, well I've
been [though the] psychiatric system, right, that's different, right and maybe the other people that you've interviewed have come up with that, that, the fear, okay cause people have a lot of fear around that, of disclosing that they've gone through the psychiatric system.

Although Mary no longer feels as much fear as she used to on the board, she still recognizes that it was there upon first joining. "Today there were two other people that had gone through the system there, at that meeting, so I don't feel quite so thrown to the wolves kind of thing but you see when I first started going there, I was really paranoid."

For some other participants the source of discomfort initially, stemmed from their perceptions of other members on the board and committee. Specifically, a few participants recognized and felt intimidated by the differences in power and status of professionals on their board or committee. Mark felt uncomfortable with the degree of comfort among all the other board members as well as their appearance of a better financial status than his:

I remember the first meeting we went to, me and [Diana], it was like, everybody comes in these really fancy dress, and really fancy suits and there you know, they're up there in society, like they're all parking in the paid parking and it was really weird because everybody knew each other and we were the new people on the block, and they had sort of an in joke that was going on and it really made, made me feel like belittled almost because they were, they were sort of an in-house joke you know and I, we, I know [Diana] and I felt, I know [Diana] felt uncomfortable and I felt uncomfortable.

Mark feels that the initial discomfort dissipated with time as he became more familiar with his role. "It's just like, everybody being born knowing how to talk and then going to school, you know, you learn, you feel uncomfortable because you know how to talk but you don't know, properly, so, it's just like familiarization or whatever."
Gerry also felt discomfort with the status of the professionals on his board but has also gradually felt more comfortable with them:

I was very, very nervous the first little while because I was, you know, an unemployed person with not really much to my credit, I mean I had a successful career at one point, but that’s in the past, you know, and I was in with a lot of professional people, people with very strong resumes and I felt, I felt a little bit intimidated, I didn’t know if I could really speak truthfully from my heart and have people listen to what I was going to say you know, but I’ve been glad to see that the board has been very responsible from the top on down.

Julie also echoed similar experiences of feeling class differences with others on the board as expressed by Mark and Gerry:

I think initially there were certain class issues for me as well that I felt that you know, I had a very different light from the other people in the room, some of them anyway, not all of them, and, initially it was kind of hard to ask questions or to talk about things in a very you know, in any kind of level, and I still struggle with that a little but again as I get to know people better, it’s sort of less.

Julie later added that:

It was interesting partly because we, [the other consumer and me], had to sort of figure how the board worked, I think initially when we went in, it was difficult to figure out exactly what we were supposed to be doing there and, I sort of felt like I was walking in on the middle of a conversation, they had sone a lot of work on mission statement and long term strategic plans and things like that and all of that had been finalized by the time we got on boards so it was sort of okay well what do we know, and I think we spent the first half of year anyway really just sort of groping around trying to figure out
how we fit in and I think I felt, in a strange kind of way quite intimidated by other people on the board, simply because their role seemed to be quite obvious, or their contribution seemed to be quite obvious and I, I said to the executive director one day it seems like the only thing I have to contribute is my sad story and I don’t really want to you know.

Rob also acknowledged the initial discomfort and intimidation upon joining and having to challenge old ways of relating with professionals:

The whole process is overwhelming and intimidating because you’re I mean, at the very beginning you’re sitting at a table and that’s something that everybody needs to know about when they first get into it, and when I try and [get] people involved I tell them that, I don’t tell them that’s it’s going to be easier you just have to sit and you’re not going to feel stress, I tell them you’re going to have to fight for your place at the table and nobody guarantees that you’ll be heard the first time, and when you’re sitting there with a bunch of people that traditionally were always telling you what to do with your life and were controlling your life and all of a sudden, you’re being parachuted in there I mean, that can be pretty stressful because that whole relationship between the client and the caregiver has to change because the way they look at you and the way you look at them has changed radically right, we’re talking about people to people here not client to caregiver, and that I mean that change alone can be very intimidating and we have to prepare people for that.

It appears that for Mark, Gerry, Julie, and Rob there was an initial source of discomfort upon entering their board which stemmed from their perceptions of the power and status of the professionals on the board or committee.

The final area that served as a source of discomfort for consumers first joining boards
and committees involved their roles and responsibilities as a consumer representative. For Jim this was expressed in the beginning as not feeling qualified to do the job because he didn’t feel he was a consumer:

I guess when I got put onto the committee ... I didn’t feel like I could be on it cause, they, I was only your average youth, like suicidal, depression oriented and you know I [have] been on medications and stuff but not, I wasn’t like your manic depressive mental illness or anything like that so I didn’t really think I was a consumer so I felt out of place for awhile and didn’t think, well what’s the sense of me being here, right, like, and then it started to evolve and they said, "well no, that’s wrong you know," and it lead into me sitting on there for awhile.

Both Gerry and Nancy felt they were cast into their roles without preparation and subsequently felt overwhelmed. Gerry said:

Well it’s a little bit like going into the deep end and having to learn how to tread water, at first you kind of thrash around frantically, because you know there’s 10 feet of water below you, but you know given a little bit of time you learn to adapt to the situation and learn how to do things, there’s still a lot of things which I can’t do, I can’t stand up and deliver a speech, for the life of me.... I still make my contribution, despite the fact that I’m not great at chairing meetings or delivering speeches you know.

Similarly, Nancy reported:

I was very concerned because of the fact that, you can see the level of participation I’m in now, I really felt that I was thrown in at the top, and I was very insecure for a long period of time and I still am because I feel really deficit in some areas and there’s no doubt about it in my mind but there I was, checked in at the top and flailing around, you know pretty soon it’s this [council], chairing the ... task force and doing this and doing
that and just feeling like I don't know what's going on really.

Despite Jim, Gerry, and Nancy's initial discomfort with their role and responsibilities they all gradually felt more comfortable with continued involvement.

Further participants experienced discomfort due to their role and responsibilities in the area of communication. Chris couldn't understand the language of the board to begin with and didn't really feel part of the group, however, she was gradually able to develop a sense of belonging. In talking about the changes in her experiences over time Chris said:

Well I see a lot of changes, I, and shifts, I wasn't interested to begin with, one of the reasons I didn't understand a lot of things, there's a lot of anachronisms that were used at you know at a meeting, a TEP and a you know, I would go home wondering what these things were, and if I wasn't feeling well I wouldn't go, sometimes I just didn't remember, I didn't have, I didn't have a focus, I didn't really have a real interest you know to stay and it just gradually the you know, association became more and more important.

Julie shared a similar experience to Chris in that she was overwhelmed and intimidated by the material she needed to understand as part of her role:

It just seemed to me that it was something that everybody else knew more about, whether they knew about [this new government mandate] itself but they knew all about cold funding this that and the other and sometimes I'd sit in the meetings and so it was sort of like walking again into the middle of a conversation that you know a lot of things weren't explained to us about how the funding worked it was sort of assumed that that everybody who had ever been involved with the program knew how it was funded or something like that and, so there was a lot of homework that I found that I had to do ... sort of again that feeling that I should know this stuff you know, what am
I doing on the board if I don't have some sense of this stuff already, and it seemed that the other people who were new on the board, they came from backgrounds where you know they did have, they all knew the same people, it was like they were all part of that, sort of background, professional caregiver type background.

Rob also felt intimidated originally by the responsibility and role of consumer representative which he now recognizes as stemming from self esteem issues:

I felt like there were so many times I was just in over my head, where I kept, I guess it was a self-esteem thing, is why do these people want me to get involved and I would just sit there for hours at a time and just feel so inadequate and useless, and, you know, I would listen to these people talking back and forth and discussing you know how consumers should be trusted and I said there needs to be somebody else here, somebody who understands this process, I mean, it's just beyond me, and I kept thinking you know there has to be a better way.

Despite Rob's confidence in his role on boards and committees today he initially experienced feeling insecure and overwhelmed when first starting out.

In summary the participants experienced discomfort such as intimidation or not fitting in upon initially joining their respective boards and committees. Many participants expressed analogy's or cliches for this experience, being "parachuted in", "thrown in at the top", "walking in on the middle of a conversation," and "going into the deep end and having to learn how to tread water." In looking at the experiences of the participants upon first entering boards and committee there were three main areas of discomfort, revealing their status as a consumer, the power and prestige of professional members, and the roles and responsibilities of being a consumer representative. On the whole, it took the participants some time to settle in on boards and committees.
The Experience of Stress and Exhaustion

“It takes a lot of energy and it’s a lot of analytical sort of energy to be doing board work, and a lot of political sort of things and stuff like that and it’s, it’s really an unusual kind of stress I think.”- Julie

Among the accounts of the participants emerged the common experience of stress and exhaustion as a result of board and committee work. The stress and pressure stemmed from the board process and group dynamics for some of the participants. Specifically, the slow process of boards, their political nature, as well as working with others, were all stressful in the eyes of some participants. A further area of stress was that of the position or responsibilities associated with consumer representative, such as public speaking, maintaining a positive image, involving other consumers, and firing another consumer. Some participants found it stressful to review their mental health history as part of their role as consumers representative as it was painful and stigmatizing. A couple of the participants also found it difficult to deal with the time pressures, in that they had too much to do and not enough time. Moreover, other participants discussed feelings of exhaustion and burn out from involvement on boards and committees.

The subtheme within this theme is an exploration of the coping mechanisms used by the participants to deal with the stress they encountered on boards and committees.

The participants experienced stress in relation to the board process and group dynamics. Mary had to deal with a high stress level after board meetings:

I mean I leave these meetings here, committee meeting before the, and I just like I rage, right, on the bus, one time I got on the bus from here, last winter and I got into [the city], I was going into [the city] and I was smacking myself right in the bus, I was going like this right, it was like maybe if I hit myself I’ll be able to under, I’ll be able to deal
with it, I'll be able to, I just get, I just get raging inside me and I get really messed up you know it's part of my job and it's also something that maybe later people can benefit from, but I mean it's really like I put myself through the mill, it is, at times, it is, but I mean, I just, I do as little as I can if it, and, I leave it. I don't expect changes.

Similarly, Julie sometimes feels overwhelmed with her board meetings, specifically, with the enormity of the tasks they face and the little tangible evidence that change is actually taking place.

It seems like such a big job, it seems like such a big task, there's such big questions that we're looking at that it's kind of overwhelming, I think in a way it would be fun to be you know, worrying about that staff morale or something like that you know, worrying about something a little more tangible ... it's very analytical, you know and that's a hard way to think a lot of the time, in some ways even like what you do is, it's a tangible kind of thing, you're helping people get their heads together about finding work and getting their self confidence and things like, and that I understand you know, but I don't understand sometimes you know, why you have to come up with a definition of, of caring of why you have to come up with a definition, what was one we were hashing out? It is what is meant by consumer involvement you know, it gives me [a] headache to think about those things in a way because you know it means, it means you know, it's like what is the question here?

A few of the other participants experienced stress and pressure in regards to the group dynamics that are part of their board or committee. In particular, they found it stressful interacting with other board members who were troublesome. For example, Nancy relayed a situation that was stressful for her in which she found herself stuck between an influential consumer and a mental health professional:
It’s not only consumers that use you either, it’s also the system, we had a [special event] ... and one of [the] things that happened there was that [Joe] wanted to, at that [special event] there was a lot of problems with his participation but he wanted to get all the important people together at his table so he could brainwash them, and well not brain wash them, but talk to them about [this issue] and get his points across and you know just be there, be there, and one of them, [Bob] came up to me and said, “Nancy, [Joe’s] after me to sit with his table but I really don’t want to so can I sit with you?” And I said, “sure, you’re welcome to sit there, anybody can,” and this [Bob], of course we all know he’s a little political animal and protects [Bob] first but this really ticks me, because as then [Joe] was continuing to get him to sit there he said, “ah no, Nancy’s asked me to sit there, and she asked me first, I’m going to do that.” Then [Joe] came and starting turning the screws on me, and I go why wouldn’t [Bob] have just said I prefer to sit there, instead of letting me take all the flack for him ... why couldn’t he just stand up to [Joe] and say I’m not doing it, and that really ticked me off.

Nancy later added that this event increased the pressure she was under. “I didn’t need extra pressure and I didn’t need [Joe] harping onto me and [Bob] could have dealt with that more up front himself, but that way, I was the bad guy and he was still the good guy.” Mark experienced stress in dealing with other people on the board, in particular a woman whom he found to be troublesome:

I’m not interested in participating well, I’m interested but I don’t feel it as important to participate with this other woman because no matter what I have to say or no matter what I do, she’s going to do it all herself anyways, I’ve experienced that, I mean we were, we were having a [special event] ... and before [Sam] got ill at one of the meetings this woman said, “I neglect to,” or “I negate to express my views on the
opening of the [special event],” so [Sam] gets sick, he’s out of the meeting and this woman just bulldozed, just said “this is, this is the way I want, this is the way it’s very good,” and you know, and a third of our money went on getting this professional ... I mean it’s a crock of shit as far as I’m concerned, I mean I would have very much liked it better if one of the committee members did it, you know if we were into spending that much money we could have gotten somebody from [elsewhere].... I mean I didn’t have any other suggestions at the time, I frantically looked for other options but didn’t happen and, I don’t know, it really upset me the way this woman just you know, ended up you know.

A few of the participants experienced the pressure to perform on boards and committees which involved being expected to do a good job in speaking and representing consumers in front of the other members on a board or committee. Mark agreed that he is aware that in risking and speaking up there is a danger of being shot down by others. This increases the pressure to get it right the first time. Jim shared Mark’s experience of pressure and added that the pressure could be mediated depending upon the support available at the meeting. For example, if Jim knows he had support for his views then the pressure to perform is diminished in comparison to when he is unsure as to who supports his ideas:

It’s not necessarily the stress of knowing what [are] these bureaucrats going to say cause personally, I don’t give two hoots right, it’s more the people that I am working with ... it’s not the fear of the known, is more of the fear of the unknown like that’s where the pressure to perform comes in, it’s like okay, do they agree with me or do they not, oh, oh, like if I knew they all agreed with me I’d be on top of the world right, but I don’t know that all the time so that’s where that pressure to perform comes in.

Similarly, Nancy experienced the pressure to perform when she was working with an
influential mental health professional:

There’s a fellow from [another country], he thinks I’m wonderful and so long as he stayed there and I stay here he’ll continue to think that, and that’s nice because I think he’s just great, but when I’m around him it’s very very threatening because I’m afraid that, you know he’s going to find out who I really am is nothing, and so the whole thing is a threat, that some day people will find out that this has been an act, and that’s not really me.

She feels the stress and pressure of maintaining a positive image in the eyes of others and is afraid that they might actually find out what she is like and dislike her. In short, Nancy, Jim, and Mark experience the pressure and stress of having to put on a performance of competence despite their feelings of inadequacy.

Stress and Pressure due to Responsibilities as Consumer Representative

A few of the participants reported stress and pressure because of some of their responsibilities as consumer representative. For example, Julie experiences stress in trying to involve other consumers in the organization. “What I am trying to do now on the board is try to create opportunities for the board to be in contact with lots of different people with mental health issues, so that they can get you know, perspectives from lots of different people and also hopefully to line up other consumers too, to help out on the board because it really is a bit of a burn out, it seems, it’s kind of stressful.” Likewise, Nancy experiences stress in knowing that her responsibility is to represent consumers. She uses herself as a model to portray a positive image of consumers:

People say to me well you don’t have to do it, then you think well somebody’s got to do it, whether it’s a case of, I always panic and end up feeling that kind of self or what, I don’t know I have to learn to trust and yet that somebody will get the job done but that’s
always worrisome if you end up with it not being done and then reflecting on consumers ...
I mean you get people saying consumers have a right to make mistakes and certainly we do as other people, they can make a major mistake and say oh well, we’ll do better next time but for consumers the major mistake is not forgotten, it’s always there reflecting on the whole of consumerdom, so you feel the need to make it right.

Mark not only finds some of his responsibilities to be stressful, but that they can conflict which is even worse. He found it difficult to represent and support consumers as part of his role on the board and, at the same time, fire a fellow consumer from the organization. “It’s not particularly healthy anymore, I mean especially when you know, you end up firing your friend… and that’s that’s why I want to go, you know, I’d rather just stop doing all this stuff.”

Jory and other members on her committee experienced stress because of their success in planning and hosting a special event. Jory believes it was stressful for them to be successful because they have grown accustomed to being defeated:

I think we went through quite a difficult period right after the [special event], we all worked together so well and then after it was over, started nit picking at each other even though we had done a good job, we were destroying each other for a while there, month, and as I look back on it now … it was a turning point for the council, it was the real, the first real success, and up till that time we could work together and different ones of us had become sick, couldn’t take the pressure … of the [special event], couldn’t take the success of the [special event], sometimes it’s harder for us to be successful because we’re so used to being defeated, or not just me but some of them really badly, we’re used to, they can’t face success … and you know I find it easier to be, harder to be successful then most people, but some of them are even worse than I am, and I guess
[it’s] to do with self esteem and self concept.

Jory and other members experienced stress when they were successful and Jory links this to self esteem issues.

Experience of Stress in Revealing One’s Mental Health History

A further area of stress for the participants involved the realm of mental health. Both Mary and Julie experienced stress in relation to their mental illness and participation on boards and committees. Specifically, Mary feels it is stressful to remember and discuss some of the mental health issues the board and committees face. According to Mary, people want to put their mental health history behind them, however, boards and committees don’t facilitate this, in fact, they do the opposite. “Most people that go through the psychiatric system, when they come out of the hospital okay, they want to forget about it, okay because if they forget about it then it didn’t happen, it is so painful okay and so you’re, you’re kind of struggling between you know, trying to forget about it and then the fear that it might happen again.” Julie feels it is hard to expose her past mental health history or “sad story,” yet this is something that is expected of her as a board member:

The nature of the mental illness and the way it affects you when the spotlight put on you for that kind of thing, you know you’re still dealing with social stigma and it is an uncomfortable thing to sort of come out in a sense and put yourself in a position where people are seeing you in a light, so it is stressful when the people while are actually on your board as well are doing it too.

Julie later added that it was not only stressful but sometimes emotionally draining, “because you’re really revealing a lot more of yourself at any of these meetings than the other people are, [they] always have the cover of whatever suit they’re wearing that day whereas you just have to be there and talk about.”
Experience of Stress Due to Time Pressures

A number of the participants reported feeling stress and pressure because of the many responsibilities and things to get done yet not enough time. The time pressures on the participant were problematic and stressful, for example, Rob offered:

It’s just that there’s too much demand on you too, right, if you start like, you know you start [to] wonder, I mean it’s about like you have about 18 different personalities because you go to the table as this representative and you go to the table as another representative, at some, at some point, I mean I have to look at my book to see what committee I’m going to, and who the hell I’m representing, I mean that’s how crazy it gets, and because there’s so few of us, I mean we’re all spread so thin it’s just nuts ... you haven’t got the time to sit down with people and say this is what we need right you know, and once you’re known in the community, you know, especially for people that public speaking or facilitating at workshops, I mean they just drive you crazy, and I mean most of them won’t take no for an answer, I mean I say no all the time now because I have to, but there’s not enough time in the day, but I mean it’s just nuts, I mean the phone never stops ringing.

Like Rob, Nancy also experiences the pressure of having too much to do and not enough time. She is also in a position where she needs to say no to different committees in order to reduce this pressure:

Professionals, you know, they just, or people who seem on side but don’t understand you like I’ll say I’ve got to give up something so when the [organization] started to sort of what I thought was railroading me it was a case of do I hang tough and make them accept me and not fall into their trap, or do I just free myself of that burden, and the minute I said I had to free myself of that burden because I couldn’t cope anymore, the
person that was theoretically sympathizing with me and this feeling of being under and over worked and the whole thing, "oh, well when you do, come and see me at this, I've got this thing I think you should do," and there always harping at me to take jobs, they don't really understand.

Similarly, Chris states she needs to pick her priorities and balance her committees in order to deal with the time pressure. She also needs to balance the time pressure from boards and committee with that of the needs of her family.

I mean my July and August I have spent so much time with our local board, so many hours I mean typing a report, and you know, writing letters and that, I've just spent a tremendous amount of time that fortunately it's July and August and I didn't have that many meetings out of town, you know, but I couldn't pursue it and keep doing it in September, cause I just, you know, I think that's why I have to pick my priorities, my [one child needs my help], and my [other child needs help] and then there's my husband who likes some quality time once in a while too ... sometimes it's too much, like I sometimes July and August I have [been] so tired sometimes that I just, in fact last year I came back from a board meeting ... and I didn't get up for 6 days, I got sick and I just, I mean I got up you know, go to the bathroom and stuff like that.

In addition to stress and pressure, a number of the participants were exhausted by the demands made of them through board and committee work. As Rob states, "you have maybe 12 or 13 consumers that are asked to serve on 60 different committees, and we're exhausted now, I mean I can't even begin to keep up with my work load." Both Jory and Julie echoed the fact that their responsibilities could be exhausting and energy draining. A particular time Chris experienced exhaustion was when she went on a trip abroad to represent consumers. Upon returning from her trip her stress level increased because she was so exhausted. In
talking about her stress she said, “when I got back from [the trip] and I was pretty tired out, it got to me a lot worse than it does right now, it’s not, it doesn’t wear me down as much, but it still you know, takes it’s toll.” Likewise, Nancy also reported being exhausted at times, “I can’t keep up with all the paperwork, it’s just impossible, I’m threatened by it, my mind goes blank and it’s just become such a burden that [I’m] dead again and can’t get up because of what I have to do, I can’t face that job ... I haven’t been getting up all week, [it’s] just a struggle sometimes to keep going.” For a few participants exhaustion is intertwined with their experiences of stress and pressure on boards and committees.

Experience of Burnout

A final area discussed by the participants in relation to stress and pressure was that of burnout. Rob said, “yeah, burnout’s a problem.” Jim echoed a similar level of stress in his example, “I say [it’s] like this, combust, have you ever seen those movies where they got like the, where they got like the, where it pushes together and sometimes they got the scene where they push two walls together ... I guess the best feeling, the best description I can give to that is you know, I feel like I’m trapped and then it’s all coming in you know.” By the same token, Rob said, “I’ve been over my head so often like you know, I’ve been down and you know, I’ve been under third time a couple of times now, just managed to get back out again.” In comparison, Julie also experiences burnout because a great deal of her time and energy is being directed at mental health issues:

I’m really worried right now, I mean I’ve been doing lots of volunteer work with mental health and because of my [other interests] and stuff like that I’ve been focussing a lot on mental health issues recently and I’m sort of burning out on it, now it’s like I want to I want to be involved with different people, I want to be involved with people with different problems than the ones that I have you know ... a little overloaded, it’s like
there's this I think it, maybe the danger is it happens in any committee where you sort of you know, hang around with people who are, the only connection you have with them really is one particular facet of your life, you focus exclusively on that facet of your life or almost exclusively ... it is narrows the rest of your life really, all of a sudden you're not, you're [not] exercising your potential in any other way and I think it's especially important of you have an illness of any kind that your not constantly dwelling on your illness.

Mark is also experiencing burn out from his work on boards and committees. When asked if he is burning out Mark said, “yeah, I've been doing that for a while and I'm becoming less and less effective in meetings, I just don't know how to quit, I don't know what to say, I don't know what to say to make everybody feel good and still go straight with what's happening to me, I mean I could just say, right burn out and I quit or whatever.”

The effects of burn out have been detrimental to Mark's physical health:

I'm contemplating just going back to my old lifestyle where I was, you know, I mean I don't know how to say this now, where I was my main concern, and my life was what I was thinking about you know, it's whether I'd do this or do that or the other thing, not whether you know, I'm doing my best, where I was my main concern, not where in my travels the way it is now, my main concern is to do things better for other people, get things better for other people like me and, you know, I've neglected myself.

In a similar fashion Rob discussed the way in which burn out has influenced him:

Well there is burnout I mean, I what happens, the way it affects me is I'll walk away from the committee, and the way burnout manifests in me is when I get to the point where I feel that I have no where nothing more to contribute from my, from my perspective and that's it’s either time for either somebody else to come along or I realize
that this committee is a do nothing committee, and my perspective is not always balanced, I mean that’s the way I see burnout when I’m not when I’m not willing to participant anymore and the thing that I’ve learned about burn out is that when you’ve reached that point then you have to go because what you do is you harm the work of the committee and you start to behave in a ways where people start to get the wrong idea of what consumers are and what they represent and I think that when you start to damage the consumer movement then you need to get out ... I think it’s as much of a feeling as you have [gone] as far as you can go, with that committee is that you’ve said what you had to say, you’re not being heard and maybe it’s not, I mean it’s partly your responsibility too, because maybe in effect you’re not bringing to the committee what you need to bring to the committee and you’re trying, you’re trying to push things beyond what the committees mandate is and the only trouble is that you don’t realize it at the time, then it’s time to go.

In summary, a common experience among the participants was that of stress, pressure, and exhaustion on boards and committees. Two sources of stress included board process and the enormity of the issues that were being dealt with, as well as group dynamics involving disagreement with others. Further participants experienced pressure in terms of having to be competent despite feelings of inadequacy. Stress and pressure arose from a variety of responsibilities the participants had as part of their roles as consumer representatives. Interestingly, Jory reported that success was sometimes stressful because she was used to being defeated. Other participants indicated that dealing with their history of mental illness on boards and committees was also stressful. A number of people encountered time pressures in having too much to do and not enough time. Exhaustion was also experienced in relation to stress and pressure. Furthermore, a few of the participants discussed their feelings of burn
out and the effects of it on their life and work on boards and committees.

The Participant's Means of Coping with the Experience of Stress, Pressure, and Frustration

“I either try and talk to somebody that is there that I know I can talk to, or just try and let it go don’t even, just push it aside and don’t even worry about it. Hopefully it doesn’t come back.” - Jim

The participants encountered stress, pressure, and exhaustion as well as frustration as part of their experiences on boards and committees. Each participant also discussed the means through which they were able to cope with the stress and frustration. A number of them mentioned having to change their perspective or cognitions in regards to board and committee work in order to survive. By manipulating and controlling one's thoughts the participants reported being better able to cope with the stress and frustration. Furthermore, a few participants mentioned the importance of support from within the board as well as in one's personal life in coping with the stress and frustration. The setting of boundaries with others was also a useful tool in dealing with stress. Moreover, a couple of people mentioned humour and its importance in buffering stress. Further participants reconnected with nature or their spirituality as a means of coping. A few people reported that they had used substances such as anti-anxiety medication and alcohol to relieve stress from board and committee work.

The most frequently reported method of coping with stress and frustration on boards and committees involved altering one's cognitions about the events. This method helped the participants to continue participating in the board activities. For example, Julie experienced enormous stress and frustration due to the slow pace of the board and what could be accomplished. In the end, she found that by altering her perceptions and expectations she was able to cope more effectively with the stress and frustration:
Well certainly since I've started, my definition of what could be accomplished has changed you know, I feel that I had to really change my expectations in order to survive on that board because, or else I just would have exploded with frustration I think ... I think when I went in there, I mean I didn’t know what to expect when I went in there but I sort of, I guess I thought that we would be doing more things like active research and investigating things ourselves and things like that, and I've discovered that the board doesn’t even do that as a policy board, we basically take information that’s given to us from others and I don’t like being spoon fed stuff you know, I didn’t feel that this was necessarily a good way to be getting information and yet I understood that it was very time consuming you know, to be doing the information gathering that maybe that wasn’t the role, so, what I guess I had to change was, what type of decisions we were going to [be] making and what type of information we were going to be looking at.

Chris reported that she copes with the stress and frustration by seeing negative events as a necessary part of the journey towards positive changes. Chris has faith that there is a light at the end of the tunnel and uses this to get her through the tough spots. “I see that in the journey there has to be the good and the bad and that acceptance that there is going to be that and I'm going to work through, but there is a light at the end of the tunnel and I can see it and I'm going there and it involved both sides.” She later added, “the light at the end of the tunnel, this is one thing I’ve told consumers ... to get a light you have to have a negative and you have to have a positive, and everybody has negative experiences, you know but it we put some positive into it and start working with the positive, that’s when we get the light at the end of the tunnel.” Nancy also echoed that positive experiences and being able to look to the end of the tunnel helps her cope with the stress and frustration as well. “I haven’t been getting up all week, this [is] just a struggle sometimes just to keep going and then I’ll have a
good day ... it’s just every once in a while either a light shines and somebody else pulls the string on or I manage to pull some strings for myself and kind of dedicate and say okay Nancy, look at where you’re at, look at [your] head space, re-evaluate, re-think, pick up your phone.”

Mary copes with the stress and pressure of board work by compartmentalizing the experience and trying to turn off thoughts about it when she is on her personal time. Mary believes this shutting off process serves as a protective device not allowing the stress to consumer her:

It’s like I do this, and then I just shut the door on it right, the other things I do is like I’ll be brushing my teeth and at home and I’ll be thinking of the proposal ... or else I’ll be having my dinner and I think about the ... group or, and that is part of my life, right, that is part of my life you know, this is like, it’s just like this little compartment right, and the only way I can deal with it is to do that, is to compartmentalize it ... shut the door on it.

Mary stated that she also uses denial to cope with upcoming events that could be stressful. She prevents herself from thinking about them so they don’t emotionally overwhelm her:

I’m really great at denial, I was really excellent at being in denial right, you know and a certain amount of denial is good you know, I cannot function if I was to think of this, I’m going to [this organization] tomorrow ... to ask these two guys [to] run a group so I mean like I don’t want to get a whole bunch of emotional build up you know sort of thing around that and again like somebody else it’s like I handle it ... I compartmentalize it, right, and then when it’s time to deal with it then I can pack it up and I can deal with it, but I’m not going to be, when I leave here ... I go home and do my own thing right.

By compartmentalizing board and committee work and keeping it in perspective and balance
with the rest of her life. Mary finds she is better able to cope with the stress.

Two other participants utilize positive thinking in terms of their commitment and trust in themselves as well as others as a means of coping. Nancy stated that one needs to know why they are involved and be committed to this goal:

I think you need, this sounds terrible, I feel I am, I think you need a lot of, you have to either [be] stupid or have a lot of guts to hang out in this and take these risks and put up with all this crap, you have to know what you’re doing and to believe it’s right, you have to be really committed or it’s going to kill you cause it can be so awful, so terribly terribly awful, and yet you feel in spite of it, it’s so important, you must be tough. Like Nancy, Julie also recognizes the need for her to be strong and to have faith in herself and others:

What I’m starting to realize is that it’s up to me, it’s up to me to keep perspective on this, to have support, there are board members that I have a reasonably good relationship with, basically trust people on the board, and it’s, I guess it’s a hare and turtle sort of situation, I think the slow and steady go in this race not to burn myself out, on issues and not to get too too attached to the outcome of things, but to also know that, if what I feel is necessary, really is necessary then the time will come when the elements, the situation will line up and it will happen because it will have to.

Rob provided another example of utilizing one’s cognitions to cope. He states that he tries not to let himself take things too personally, in fact he prepares himself to receive flack from others and these beliefs help him cope with stress:

Well you know part of the problem too is that you know, you can’t take that stuff too personally like I mean it’s a learning experience because when you’re you know, when you’ve got a fairly high profile and you’re seen as sort of as a leader, especially in a
movement where there’s a lot of visibility for you know say just a few people, but people are going to take shots at you, I mean for a lot of reasons, people may have justifiable criticism, may not like your style, they might be jealous [and stuff] like that right, and a lot of times the shots aren’t legitimate, it’s just meant to take you down and to make you feel bad about yourself, and I used to take that stuff personally but I don’t worry about it anymore.

A number of the participants coped with stress and frustration by eliciting support from others. Having someone to talk too either on or outside of the board was useful in buffering the stress. Jim states, “I [try] and talk to somebody that is there that I know I can.” Julie also recognizes the need to talk to someone, however, this person doesn’t necessarily have to be involved with boards and committees. Julie finds a good stress releaser is talking to her husband about her concerns:

I think anybody who would go into a board as a consumer would have to be aware that it’s sort of, you got to have somebody to talk to that’s outside of the organization while you can vent your frustrations to, took me a long time of just coming home and you know, going over the whole thing with my husband, you know to be brave enough to go to the [Administrator] and talk about what really were some of my concerns and frustrations were.

Moreover, Nancy recalled an incident where she needed someone to talk to about an argument she had with another consumer. The person she eventually spoke to helped her cope with the stress and plan how to continue working with the other consumer:

I didn’t go to the [event] the first day, was to [go] the second day, and I had not included the consumers enough but I didn’t know them enough and I felt the time lines were short, I was stretched and I didn’t, [Joe] got into a big snit, he phoned me up
because this was happening ... and he should have some say about it ... anyway, I was getting, I knew as soon as I got home and turned on my answering machine I was in trouble because people were phoning and saying, “Nancy call me, Nancy call me, Nancy call me,” and these were people who had been there that day and I thought, oh shit has hit the fan, what is happening here so [Joe] was creating a big stink and everything and they wanted to know how we were going to deal with it the next day, some of them weren’t going back to the [event] because they couldn’t handle him anymore, he had been putting so much pressure on that day and thought well what do I do? How am I going to get over this anger that I feel and how can I deal with [the] situation properly, you know, those consumers are sure a problem kind of an image, and I was thinking of [this mental health professional] but what she always does where [Joe] is concerned is, “oh Nancy, why can’t he be a members of your council, oh he won’t, poor little [Joe],” and that of course (non-verbal of angry), then I could have phoned [this other mental health professional] but then I knew that if I phoned [him] for advice and to talk this out to, he was going to buy into my anger and I thought well that’s not going to be productive because I have to do something about the situation so I thought [she] is going to get me more angry and frustrated, [he] is going to buy into my anger and that won’t help me at all, so I ended up phoning [this woman] and talking to her and she helped me see where I could deal with the problem better next day and I did try too.

Conversely, another participant finds it necessary to set boundaries with others so as to prevent them from overwhelming him with issues:

Part of [it] is too, is being able to cut of, like I’m accessible 24 hours a day ... at some point I don’t want to deal with somebody’s problems all the time right, and I have to be able, and I’ll tell some friends that are consumers, when they start whining and bitching
about not, you know having this, I said, “do this on my office hours,” I said, “you’re at my house because we’re friends, we’re out because [we’re] friends,” I said, “I don’t want to deal with your problems you know, and stuff like that, and I mean I think that’s healthy because I mean there has to be something else besides this.”

For Rob, saying no to people and creating boundaries is important in mediating his stress. Nonetheless, Rob states that this is not always easy, “I’ve never quite learned how to do that, you know, I’ve got a whole office full of people that try, keep trying to tell me how to say no.” Rob sees the importance of making his expectations of others clearer whereas Nancy and Julie solicit the support of others in dealing with problems.

Nancy, Julie, and Rob believe humour is an effective way to mediate and diffuse stress they encounter. As Rob states, “what I’ve said to other people is that you need to loosen up a little, because if you take this stuff too seriously it will just drive you crazy, I mean you’ll end up in the [psychiatric hospital].” Julie echoes this idea as well, “being able to laugh about it, and I find there is something very healing about laughing about really horrible things.” Nancy stated, “I’ll make light of it because it was really bothering me.” It appears that for some of the participants humour is a valid means of coping with the stress and pressure.

Both Jim and Chris draw strength from their spirituality in coping with stress and frustration. Both Jim and Chris draw strength from their spirituality. For example, Jim enjoys nature so he uses it for a source of support when the pressure overwhelms him. “Well I guess what they say is I hug a tree ... cause I’m like a nature bug I’d guess you’d say, you know if I don’t, I feel that’s just part of my spirituality, getting in touch with nature and stuff like that.” In association with Jim, Chris also recognizes the importance of her spirituality, “I mean I do have a faith which for years and years and years I didn’t have any kind of faith
at all, like I just felt there wasn't anything out there, but I do have a faith."

Both anti-anxiety medication and alcohol are substances that participants used to help cope with the stress and frustration. Nancy views her use of anti-anxiety medication to cope as unfortunate, however, it allows her to participate so in the end the benefits outweigh the risks:

Well it's an unpleasant way to cope but there are a couple of groups now that I find that if I take the Ativan beforehand at least it rounds off my rough edges, so that I'm less reactive to the individuals ... my doctor doesn't approve of that as far as she's concerned than I should be off those committees if they create that kind of stress but I don't agree with that, you know a couple of Ativan once or twice a month isn't a major thing, and it's sort of my problem, then I have to deal with it the way I can, and I don't want to be reactive in some situations, I want to be, well I don't want to be reactive ever, except in a positive way, but when it affects the meeting and leads to its deterioration, then [I] can't afford that.

Mark also uses substances in particular alcohol and tobacco to cope with the stress. "A lot of the time I've gotten into the habit of some of the meetings when I get money, going to the bar and, and not getting blasted but having enough beer to make me stagger a bit, like 3 pints, or 4 pints, and it makes me feel a 100 percent better, you know, the stress is gone and after all the meetings I, you know, relaxation smoke." The use of alcohol and tobacco to cope is disconcerting to Mark and he realizes that the stress and frustration he is experiencing is playing havoc with his life. "I've neglected myself from about, you know, counselling, doctors, appointments, physical problems, and then I start drinking more and I start smoking more, I, it's really bothering me whether it's worth all the personal anguish."

Rob used to cope with the stress in his life, including board and committee work, by
drinking alcohol. He has since quit using alcohol to cope and has thrown himself into his work, nonetheless, he realizes the need to learn how to relax:

I didn’t cope with it, about 5 years ago, up until about 5 months ago I’d been drinking every day since then and that’s how I coped with it and then I found out that I wasn’t really coping, I was just you know, getting sicker all the time, and how I cope with it now is I, I just throw myself more into my work, I’ve never been able to relax, I mean if somebody was basically designing a survival guide for [a] mental health advocate they wouldn’t use me for a model, because you know I have a lot of self destructive tendencies ... but I mean I think I’m learning, but I don’t know how to relax and I don’t know how to not to work right, I mean for me, for me, work is work, and at the same time it’s my social life too right, and so it sort of becomes one continuous thing like you get up at 6 in the morning, you go to bed about midnight and it’s all, it’s all one thing, I mean I might not be actively working all the time but usually that’s what’s happening with my brain, it’s just worrying all the time right.

In summary, the participants have a variety of means to cope with the experience of stress on boards and committees. A number of participants cope by altering their perceptions and cognitions toward events or try to push the problem out of their conscious thought. The participants talked about seeing a light at the end of the tunnel and having faith in the process. Another participant found it useful not to take things too personally. A further means to cope was that of eliciting support from people either within or outside the board or committee, Conversely, one participant found he needed to put in place boundaries to prevent people from overwhelming him with their problems. Moreover, two participants stated that their spirituality gave them strength to cope while others utilized humour. Finally, a few participants reported using substances to cope which was recognized as a poor means. In
short, the participants offered a variety of measures through which they cope with the stress and frustration of board and committee work.

Insights Provided by Participants That Were Not Commonly Shared

Some insight was provided by the participants regarding the shortage of consumers on boards and committees as well as suggestions for increasing involvement. Nonetheless, the insights and suggestions were not common as a group. The purpose of this section is to increase awareness and understanding of what might be useful to increasing consumer participation. Despite the absence of commonality, the ideas offered in the area of facilitating consumer involvement will be examined.

The Shortage of Consumers on Boards and Committees

The majority of the participants interviewed reported a shortage of consumers who were willing to participate on boards and committees. There was a concern that only a few consumers can not adequately represent the views of all consumers and that eventually people serving on boards and committees need to be replaced. The rationales offered for the lack of consumers on boards and committees varied among the participants such as consumers weren’t interested, the fear of being in conflict of interest, and that consumers themselves have failed to recruit others.

Many of those interviewed felt that additional consumers were needed to take on board and committee roles. Part of the rationale for this belief came from a need to have more consumers lend their views at board and committee level. Gerry said, “I have the need for more consumers, for more involvement in that you can’t speak for all consumers and can’t necessarily represent all people.” Julie stated, “you know talking about mental illness it’s so hard to generalize about it you know, it’s so hard to know what you can really contribute as a consumer and I guess here we come to the crux of the matter in that in a way it’s the
number of consumers that’s the limitation here, if everybody had some experience of mental illness who’s on the board I think it would be easier.” Both Julie and Gerry feel that more consumers should be involved on boards and committees in order to provide a more balanced viewpoint. In addition, Jory also feels there is a need for more consumers on her council and a further issue she faces is that current council members need to be replaced. “We need more, a more organized, a more well consumer turnout for these councils, we need to go, I mean there are some that are doing it slowly and building on their own things, but some of the ones that we have also need to be replaced.” Having more consumers on boards and committees bring additional views, as Gerry states, “I’d like to see more consumers because, because we need more voices of experience, experience with the system and experience with the illness, to come forward and speak.”

A few participants provided reasons for the shortage of consumers on boards and committees. One reason, shared by many participants, was that people were just not interested in board and committee roles. According to Mark he has tried to get other consumers involved but found they were just not interested. A further problem he faces is that even if they are interested he needs to consider the views they will bring to the board:

One of the reasons I’ve done so much is because I haven’t been able to find, find people to do it with me. You know, all my friends in [the city] weren’t interested in talking about mental health, you know maybe, maybe you know a lot of people say they are interested but you also got to look at where they’re coming from too, you know, I mean I’ve had people in this one guy that was being, over done by the committee, I mean he’s got a totally different ideas than what I have.

Similarly, Nancy also feels that there are consumers out there who could take on board and committee roles but they are not interested in taking up a lifestyle of participation. “There
are indeed only 20 mental health consumers in the whole province that can do things but I
don't believe that, I think they're there some place and it's just a case of people who are
more able to do things have not chosen to make this their lifestyle, they've gone on with
some other life and for some reason we are obsessed with this one and stay with it.”

Furthermore, Chris feels that people have assumed that consumers, as recipients of mental
health care, should be interested in bettering the mental health system, however, this is not
always the case:

They figure that because they’re consumers of the system that [they] should want to do
all these things, well I ask why the hell should they? You know people that you know are
having a hard time, their rent is going up and their comfort allowance is [decreasing] and
they should be concerned about improving the mental health system, I mean like that is,
there's no rationale to me.

Chris doesn't see consumers being interested because of all the other burdens they have to
carry. Julie went one step farther and outlined what kind of consumers would be interested
in participating at board and committee level. Julie states:

I think that you know, certain types of consumers are going to be attracted to doing
board work, they're going to be people who you know are interested in teamwork and
interested in organizational issues probably more analytically minded than some other
people you know, I think other consumers might be happier with you know playing other
roles in the organization and certainly I see more and more consumers doing that and
different programs.

A further rationale provided for the lack of consumers was based on the fear of being in
conflict of interest in terms of the services they are currently receiving or may want to
receive with the role of board or committee member. As Nancy suggests, it is not that
consumers are not interested in participating, rather, they are afraid that if they do they could be in jeopardy of losing or be unable to utilize the services they helped create:

What stops a lot of people from participating is that they’re worried about conflict of interest in as much as you know the whole reason why they see a service as valuable because they know it would have helped them and could help them so then they set it in place and then they can’t take advantage of it so that’s an issue I’m always dealing with, conflict of interest and you know how do we support people and that sort of thing and just what is harmful of course sometimes, people in the Ministry and people in government take a rather arrogant view towards conflict, and well that’s just the way it is, they’ve been in conflict but they don’t realize what that does to a consumer of the services to be out in that position, and they wonder why they’re not there beating down their doors.

A further view on the shortage of consumers on boards and committees stemmed from the notion that consumers themselves have failed to recruit others. Nancy states that at times she doesn’t want to invite other consumers to participate because it is such a difficult job and she doesn’t want anyone else to have to endure the suffering she has:

There are times when I don’t want to encourage people to get involved when I’m going through a really hard time because I feel like why should they have to put up with this, I’m lucky I can survive it, maybe that’s my Mother Theresa instinct coming out and my masochistic tendencies or something, I’ll suffer, I’ll be the martyr, you don’t have to, but at the same time you think oh boy, some people couldn’t put up with this because the only supports they may have would be me and am I good enough?

Alternatively, Rob believes that participating consumers haven’t helped other consumers to become involved because the responsibilities on their own board and committee take up too
much of their time:

One of the major failings of the movement has to [this] point [been], is that it has failed to get other consumers involved and that's not because the professionals weren't giving us the opportunities, it's because we just haven't done our job, I mean you know we have been so busy with everything else that we've forgotten that there are a hundred thousand people in this province that need to be given a chance.

A further reason for consumers not encouraging others to join stems from their own need for power according to Rob:

In the Lower Mainland we might have 15 or 20, an elite core or you know strong articulate consumers, our biggest failing to this point is we haven't developed any constituency you know .... there's only a few of us out there that are doing all the work, it's not because the others consumers don't want to do the work, it's because some of us won't get the hell out of the way you know, we've sort of fallen in love with the fact that you know we're hobnobbing around with these guys in suits all the time now right you know, and you forget about those people.

Both Nancy and Rob feel consumers need to take some responsibility for the limited number of consumers participating on boards and committees and to help recruit others.

In summary the participants suggest there is a need for more consumers to become involved at board and committee level. There was a concern that only a handful of consumers cannot adequately represent the views of all consumers. A few main ideas were presented for the lack of consumers on boards and committees. First of all, not all consumers are or will be interested in the roles and responsibilities of consumer representative especially as they may run the risk of being in conflict of interest. In addition, it was suggested that consumers within the consumer movement have failed to recruit other
people to boards and committees. On the whole a number of the participants felt that there was a lack of consumers at board and committee level.

**Suggestions for Facilitating Consumer Involvement on Boards and Committees**

Among the majority of the participants exists a belief that there are too few consumers involved with boards and committees. Subsequently, there were suggestions and ideas offered as to how to facilitate and increase involvement. The suggestions for facilitating consumer involvement centered around providing adequate preparation for participants first joining boards and committees, as well as providing sufficient supports while they are involved.

Based in his own experiences Mark felt it would be useful to provide education or training to consumers before starting the committee, such as communication skills:

> It's a lot of work, I don't think, I'm not going to say that I don't think consumers can do it but I think consumers should be given an edge on how to do it ... they should be trained in interpersonal communication, body language, everything you know, I mean you go into a meeting with a psychologist and you start scratching your head when you are talking, he's going to see that as something totally different than what you want him to.

Jory echoed that there is a need for consumers to have training in the areas of communication. Jory states:

> I've thought about writing up some proposals and giving workshops to consumers and helping them out with their communication skills, I've thought that I'd work as an independent and just have groups come back and forth, maybe work with consumers for them, before they, groom them a bit before they go onto a board so that they don't just all of a sudden, whammy, you know, kind of ease them into it.

Chris also sees the need for preparing consumers prior to sitting on their respective
boards or committees:

I just think it’s criminal that they put these people on board and they give them no formal training and expect them to you know sit there and participate, I mean and they sit like bumps on logs you know and other people comment, “Well they sit there like bumps on logs,” well they’ve had no training, I mean they’ve come out of a psychotic episode for crine out loud and you’re supposed to be able to have the social skills to, you know they can’t even read the minutes, most of them, I mean it takes them an hour to read a paragraph or something, they don’t have the reading skills ... I’m very fortunate I do ... they don’t have listening skills and a lot of things go, it irritates me when I hear people say, “Oh they sit there like bumps on logs,” well I guess they damn well do and it’s not their fault it’s, it’s people putting them on boards and trying to improve the system when I mean they haven’t even got their own life together.

Chris sees a great need for training and has some very specific ideas as to what areas should be covered:

What they’re trying to do is get people on boards and then they have this little handbook to help people get on boards and they have workshops once in awhile, but they don’t have any training for these people at all ... it just to me is so stupid that they don’t consider the training, you know, nobody wants to spend the money for the training and they expect people to do all this.... I want [consumers] to know what an agenda is, I want people to know what minutes are, want to be able to read minutes you know, understand that okay in minutes you know first you have you’re very basic welcome, your conflict of interest, you read your old minutes ... what a motion is, what an amended motion is, a little bit of parliamentary, you know procedure to start with .... and then you know, you get into the process of your meeting about, you know you’re
going to pass a motion, well second it, half of them don't know what it means to second
you know nobody's ever explained it to them, so that's what I mean, just the logistics of
a meeting to begin with.

Rob also believes there is a need to provide training to consumers, especially in the area
of dealing with their role and the power associated with it:

If I was designing a training package now I mean you know I talk a little bit about
politics but not so much the politics that are involved in the, in the sort of relationship
between consumers and professionals but also between consumers and other consumers,
because the consumer movement in this province [is in a] mess right because what we've
managed to do is create a real elitist group of consumers that have forgotten about the
grass roots and I mean that's a common enough occurrence when you have sort of a
fledging movement and a lot of people they get caught up in all that, in the power game
... you forget about [other consumers] because you get caught up in the board room all
the time and all of a sudden the fact that somebody doesn't have enough to eat from day-
to-day isn't important to you.

The idea of advanced preparation was a common one among Mark, Jory, Chris, and Rob.
Despite the recognized benefits of advanced training, Mark believes there are certain things
you cannot prepare people for, such as the type of people they will be working with. “The
consumers will never be fully prepared until he or she has gone to a number of the meetings
with the you know, [gone] to the group ... let them get to know the [people].” Nonetheless,
some of the participants felt that preparation prior to joining boards and committees would
help facilitate consumer involvement.

In addition to preparation, the other major area some of the participants believed would
help facilitate consumer involvement was that of providing supports. It was felt that while
consumers were involved with boards and committees, there should be certain supports in place to ensure success in these roles. Chris believed that while involved with boards and committees consumers needed supports such as food and shelter, as well as having someone outside the committee to debrief their experiences with. Chris states that she would:

... like to see this [task force] developed okay so that consumers can have support on boards when times get tough, and times do get tough, maybe not by the perception of other people but when I gave my own example, when I was going to say something, I wrote it down and went over and over it in my mind, that’s a tough time, there’s no support for that, there’s no support when an administrator does get really testy with you, there’s no support when other board members look at you like you’re a bit baffled, and maybe that is your perception, but that’s a tough time and there’s no support .... I guess what you need most of the times is just somebody to talk to you know, and because so many times you think well you’re all alone, what do you do about a situation, should I speak I guess, you just need somebody to talk to more than have to take up a psychiatrist’s time ... I think even if we only start with a hotline, you know a number of the people could call, and then, you know, get more information out to consumers on on issues you know like look at the issues, not ta da, ta da, ta da, and actually communication is probably the biggest thing.

Jory also echoed Chris’s view on the need for an outside party to be able to access for support:

What I think would benefit the consumers the most who are acting on these boards, that are participating on these boards, is to have someone like you ... what I’m saying is that we need some kind of advisor that legally that knows the law, understands consumers, and can support people as well, maybe just a phone line, like, legal aid, or something for
consumers in an advisory situation.

Both Jory and Chris feel a hotline for consumers would be a start to providing support for consumers while on boards and committees.

Other ideas regarding support for consumers while participating were offered by Mark and Nancy. Mark believes consumers should be able to have a source of support on the board or committee such as another consumer. He says, “we should be able to come with people because it’s not fair being the only consumer and not having any support and not having anybody to refer to or I don’t know what the word is but you can stop a committee process to confer with your partner or with a couple of people, we never did that though.”

Mark would like to have support in terms of another consumer on the board, alternatively, Nancy would prefer financial supports. According to Nancy there are expenses incurred while participating which is not necessarily covered by the board or committee. Providing for these expenses can be hard for many consumers especially if they rely on social assistance for financial support:

When you get your money if you do get some from boards you’re allowed to keep $200 plus 25% and you have to [give] the rest back but if you incur extra expenses because of your participation, you’re supposed to use the $200 plus 25% to pay those extra expenses not to look at it as an enhancement to their lifestyle, whereas people with physical disabilities get their wheel chairs and their ramps and the whole thing and to keep their $200 plus 25%, but we have to use it, and in order to provide ourselves with the extra supports like, I have in that little office I have a dictaphone machine, I have a fax phone, I have two telephone lines coming in, I have two computers but there’s only one now, I also have a lab top, that we got at a garage sale or a computer swap meet, I have a photocopier, and all these things were purchased at times when I have been unable to go
out of the house to do the jobs. I could do my job here, but they don’t acknowledge that I needed those supports at that time, and I know that it was, and I have a cellular phone. Nancy feels that she and other consumers should be provided with financial supports that will facilitate their participation on boards and committees.

Lastly, Julie believes that to attract more consumers to boards and committees there is a need to make their contribution obvious or tangible. As Julie asserts, “I do think that the structure of this board is likely going to have change you know, sort of find a line between the policy and organizational stuff especially if they want consumers to be involved because, you really need to be able to see a tangible result for something like this.” She later added, “I think that there are ways that committees and boards can be more friendly to consumers and can encourage more participation, and I think getting away from policies, using having specific tasks, tangible tasks is very important because then you really know, feel the sense of success in the organization that somethings happening it isn’t just shovelling paper.

In summary, many participants recognize the need for more consumers on boards and committees and shared ideas for facilitating consumer involvement such as advance preparation and providing supports. Many participants believed training in communication and board process prior to joining boards and committees would be useful. Some of the supports suggested were a consumer hotline, someone to provide legal advice, more consumers on the board, and increasing material supports. Overall, there was a belief that more consumers are needed to participate on boards and committees and a number of methods were suggested to achieve this.

Summary

There were a number of common experiences on boards and committees that emerged from the accounts of the 9 participants. Although the themes are presented separately they
can be interwoven to form one picture of involvement. No one theme is any more important than any other. Nonetheless, it is through examining the common experiences of the participants that a better understanding of consumer involvement on boards and committees emerges.

The first theme of making a contribution or helping others through board and committee work involved a sense of meaningfulness in their participation. The participants felt that their contributions of offering a client perspective, developing programs, helping other consumers and board members made a difference. The second theme of being responsible or accountable embodied the belief that they have a specific role on the board or committee that must be fulfilled. They felt charged with the responsibility of representing consumers and expressed immense loyalty to this stakeholder group. Nonetheless, a subtheme emerged of difficulty in meeting all of their responsibilities on boards and committees. The difficulties were mainly attributed to external forces, such as a lack of support, however, a couple of participants mentioned internal ones.

Another common experience among the participants was that of a power differential between consumers and non-consumers on boards and committees. The differential in power was experienced in terms of a lack of recognition, respect, status, and prestige. The subtheme involved the female participants and they shared the experience of asserting themselves despite pressure from others on their committee to take on a more passive role. They linked this experience to their socialization as women and said they had to learn to be assertive. The fourth theme was that of positive outcomes through board and committee work. The experience of friendship, empowerment, and increased self esteem were all positive results of their involvement. Friendships with other consumers as well as with professionals provided consumers with a sense of connection to others. They felt supported,
respected, and that someone cared about them. Empowerment was a further positive outcome and was defined and experienced in terms of an increased sense of respect, control, opportunities, support, and equality. It was noted by a couple of the participants that empowerment was not something that was done to them, rather, their active involvement was a necessary condition. The experience of increased self esteem and confidence was another positive outcome and included feelings of usefulness, belonging, and meaningful work. Nevertheless, a couple of the participants highlighted the danger in having board and committee work solely define one's sense of self. Nonetheless, the participants also stated that board and committee work increased self esteem and confidence because it helped them accept and resolve issues around their mental illness.

The participants also shared a common experience of disempowerment. Disempowerment involved a feeling of less power and sometimes hopelessness. Disempowering experiences included times in which they had little support from others, blocked opportunities, were bulldozed by others, and overwhelmed by the pressure to represent consumers. Further participants added that the devaluing and invalidation of consumers was also disempowering. A further negative experience shared by the participants was that of frustration. The frustration partly stemmed from the slow board process in achieving tangible results. Frustration was also experienced in relation to disagreements and abuse between consumers and other board members. Other participants were frustrated by the enormity of mental health issues as well as by unmet expectations in receiving employment through board and committee work.

The seventh common experience among the participants was that of feeling separate or different from the rest of the board or committee. This was attributed to differences in socio-economic status and the stereotypes that exist regarding consumers. The participants also
discussed how co-optation involved the threat of being separated from the consumer stakeholder group. The subtheme within this theme was the experience of feeling uncomfortable when first joining boards and committees and then gradually settling in. The participants were initially intimidated and felt out of place for a variety of reasons, however, with time they eventually carved a role and place for themselves.

The final common experience among the participants was that of stress and exhaustion in dealing with the board process and group dynamics on boards and committees. The participants experienced stress from a number of events such as public speaking, dealing with mental health issues, to planning a successful event. The participants also reported feelings of exhaustion and burnout from the stress associated with involvement on boards and committees. The subtheme embedded within this theme discussed the measures used by the participants to cope with the stress and exhaustion. Altering cognition and expectations, having support from outside sources, using humour, spirituality, and drugs and alcohol were all means to cope as reported by the participants.

Although the participants offered their views on the lack of consumers on boards and committees as well as the methods for facilitating involvement, these ideas were not common among the group. Nonetheless, they were presented because of their importance and so as to provide insight into these areas through the eyes of the participants. The participants were concerned by the shortage of consumers on boards and committees because the ones who were involved could not possibly represent the needs of all consumers. Furthermore, it was suggested that not all consumers will be interested in this type of work especially given the risks associated with conflict of interest. The participants also provided some suggestions for facilitating consumer involvement such as the need for advance preparation before entering the boards and committees in the areas of communication and board process. Furthermore,
there was a recognition as to the importance of supports, such as an outside person to confer with on legal and other matters, as well as financial supports.

In conclusion the nine participants shared the above stated common experiences despite the differences in length of participation and type of board or committee they were involved with. It is through their stories that a deeper and richer understanding of board and committee work has emerged. A discussion and implications of their experiences will be reviewed in the following chapter.
Chapter Five: Discussion and Implications

The findings of the study will be discussed in relation to the literature reviewed prior. The researchers personal meanings of the study will also be offered. The implications and recommendations for the involvement of consumers on boards and committees are included based on the findings.

Discussion of the Research Findings

This study explored the experiences of consumers as board and committee members in the mental health field. Eight common themes and four subthemes were identified.

The findings indicate that the experiences of the participants are dynamic and multifaceted. This is illustrated by the majority of literature, both theoretical and experiential reviewed in this study. While consumers report positive experiences such as contribution, friendship, and empowerment, negative experiences of disempowerment, frustration and stress were also important characteristics of time spent on boards and committees. While certain aspects of the experiences of consumers on boards and committees are congruent with the theoretical and experiential literature reviewed in this study, the themes that emerged form an overall picture of consumer involvement that is unique. No one research study reviewed in this study encompassed the range and depth of the experiences of consumers on boards and committees that were identified here.

In examining some of the characteristics of the participants involved with the study, a few relevant parts emerge. All but one of the participants had post secondary education, almost half were employed, and close to half of the participants were married. When looking at the population of people who experience mental illness, these characteristics are more representative of the estimated top third rather than the average. Furthermore, the participants were articulate and expressed themselves both orally and in writing. Although
multifaceted. This is illustrated by the majority of literature, both theoretical and experiential reviewed in this study. While consumers report positive experiences such as contribution, friendship, and empowerment, negative experiences of disempowerment, frustration and stress were also important characteristics of time spent on boards and committees. While certain aspects of the experiences of consumers on boards and committees are congruent with the theoretical and experiential literature reviewed in this study, the themes that emerged form an overall picture of consumer involvement that is unique. No one research study reviewed in this study encompassed the range and depth of the experiences of consumers on boards and committees that were identified here.

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In the current study, the participants described five potential methods of recruitment for boards and committees: through mental health professionals, recruited directly by board or committee members, contacted because of their reputation, volunteered themself, or directly forced their way onto the board. The Canadian Mental Health Association (1991) proposed four methods of recruitment, utilizing mental health professionals in getting others involved,
as well as developing formal and informal linkages. The experiences of the nine participants in this study indicate that informal linkages and word of mouth as a powerful means of recruitment, nonetheless, what is missing from the literature in the area is evidence that some participants volunteer on their own or force their way onto boards and committees. The participants in the study were not only recruited through networking with mental health professionals, but also were involved due to their own initiative and proactive stance in wanting to be involved.

The participants' accounts revealed the experience of contribution and helping others through board and committee work. The participants felt their involvement could make a difference in how other consumers were treated. This experience was echoed by White (1989), a consumer, who discussed her personal experiences on boards and committees. Nonetheless, the experience of wanting to make a contribution seems to escape mention from most of the related literature. This theoretical literature, written mainly by mental health professionals, focuses on the purpose of consumer involvement, emphasizing consumers' democratic right to be involved (World Health Organization, 1993), the potential enrichment of mental health programs (Canadian Mental Health Association, 1991; Health & Welfare Canada, 1988; Niles & Ross, 1992; Pape, 1988; Pape, 1992; Pape & Church, 1987; Reville & Trainor, 1989; Trainor et al., 1992; Valentine & Capponi, 1989; White, 1989), altering power differentials (Church & Reville, 1989; Health & Welfare Canada, 1988), keeping policy makers accountable, (Canadian Mental Health Association, 1991; Pape, 1988), education of professionals (Canadian Mental Health Association, 1991; Lord, 1989; Reville & Trainor, 1989), and debate whether it is about empowerment or improving services (Church & Reville, 1989). While consumers discussed their democratic right to be involved and hopes of bettering the system, they did not discuss the purpose of their involvement.
other than in terms of helping others and contributing. The whole notion of "purpose" in the literature appears to stem from the need to legitimize consumer involvement, however, the participants did not view their participation in these terms.

The experience of being responsible and accountable that emerged from the participants' stories involved a sense of ownership over certain roles and responsibilities as a consumer representative. There was a sense of ownership over their behaviour and recognition of the consequences of their actions, especially in relation to the consumer stakeholder group. Although the research literature does not address this area in specific, it does suggest that token positions on boards and committees will not facilitate consumer involvement (Valentine & Capponi, 1989). It would appear that all of the participants in the current study felt they were accountable for their actions and did not approach their positions as "do nothing" token positions. Nonetheless, the theoretical literature does not grasp the deep sense of loyalty to other consumers found within the participants' experiences in being responsible and accountable for their actions.

The participants revealed that it was sometimes difficult to fulfill the expectations of their role on boards and committees. The first area of concern of the participants was that of having to represent the views of all consumers with their one voice. Valentine and Capponi (1989) assert that a consumer representative on boards and committees should not be seen as providing support from all consumers. The participants in this study reported that they sometimes felt they were responsible for providing the views of all consumers. The participants went on to describe how this expectation was unrealistic and difficult. Capponi (1991) goes one step further in suggesting that non-consumer board members were never questioned or expected to represent the views of all consumers, therefore, why should consumers be expected to represent all consumers. In addition, in examining the areas for
which the participants in the study felt accountable or responsible for, there is a huge diversity among the tasks, even contradictions. It appeared that for many participants their role was not well defined which was difficult for them. Likewise, the Canadian Mental Health Association (1991) has pointed out that there is a need for well defined roles and responsibilities for consumer board and committee representatives.

In the current study, the participants shared the experience of having difficulty in fulfilling their responsibilities due to a lack of support from other board and committee members, no help in understanding the technical side of the board work, as well as little support. A number of writers (Carling, 1993; Church & Reville, 1989; Valentine & Capponi, 1989; White, 1989) have referred to the need for a variety of supports such as emotional, financial, and technical assistance in order to facilitate consumer involvement. The participants in the study experienced a lack of support as being disempowering and stressful. Conversely, having support was identified as a means of coping with stress among the consumer participants. Overall, emphasis has been placed on the need for supports by the participants in the study, and the theoretical and experiential literature on facilitating consumer involvement.

In the current study the participants experienced a power differential between them and the non-consumers which was a negative characteristic of their relationship. A power differential between the two stakeholder groups has been cited as a barrier for facilitating involvement because consumers feel intimidated and uncomfortable (Church & Reville, 1989; Lord, 1989) which was echoed by the participants in this study. Furthermore, the participants experienced the differences in power from issues around status, prestige, financial means, and exclusionary conversation. In the theoretical and experientially based literature there is an awareness that these issues and practices lead to discomfort among consumers. Capponi
(1991) has written a training package for board members that addresses these issues. However, none of the participants mentioned that such a training package was part of their board or committee work. Granted that, both the participants and the literature suggested that consumer involvement on boards and committees challenge the power differential between consumers and non-consumers (Health and Welfare Canada, 1988). In addition, a reverse power differential in terms of consumer members having more power than the other board members was also present for two of the participants in the study. However, no mention is made of this in the theoretical literature. It is noteworthy that the participants who experienced a reverse power differential also found this to be problematic.

Another experience of consumers on boards and committee was specific to female members. Female participants experienced having to be assertive and learn to speak out despite their concerns that they would be "disturbing the peace" on the committees. The female participants attributed this in part to gender stereotyping of women as peacekeepers and passive. Theoretical and experiential literature in the area does not address this experience for female participants. Nonetheless, when this experience is placed in the larger context of society, this experience corresponds with traditional female socialization and the women's movement. Overall, the experiences of the female participants highlight the power differential on boards and committees for not only a consumer role, but for gender as well.

The literature in the area suggests that a purpose of involving consumers on boards and committees is to help them increase their social contact and financial status (Pape, 1988). The experiences of the participants are congruent with the literature in that they did experience increased contact with others and subsequently developed friendships. Nonetheless, they did not see this as the purpose of their involvement, rather as an outcome. Through the friendships the participants developed with other consumers and professionals
came a sense of support and connection. Furthermore, a few of the participants also had jobs in the mental health field and felt this opportunity had come along in part because of their involvement on boards and committees. It was interesting to note that two participants expected employment opportunities through board and committee work and were frustrated when they did not arise. On the whole, the literature and participants’ experiences are congruent in terms of increased social contact and financial benefits through board and committee work.

The experience of positive outcomes has been explicated from the participants’ accounts and included the feeling of empowerment. A number of researchers (Church & Reville, 1989; Health and Welfare Canada, 1988; Lord, 1989; Pape, 1988; Trainor et al., 1992) asserted that board and committee work may be empowering because it provides consumers with an opportunity to control and direct the process of change in the mental health system. The experiences of the participants illustrate this idea, in fact, they reported experiencing disempowerment when they did not have control. Furthermore, being respected by others as stated frequently in the literature (Capponi, 1991; Lord, 1989; White, 1989), was also an empowering experience for the participants. Nonetheless, the participants perceived empowerment as something they had ownership over instead of the idea that someone or something directly empowered them. The literature on the other hand still debates between the idea as to whether empowerment is something you do to someone or they do for themselves (Church & Reville, 1989; Stapleton, 1986). The participants would argue it is something they do for themselves.

A further positive outcome that emerged in the participants’ accounts was the experience of increased self esteem and worth. The participants felt a sense of usefulness, competency, and that they were involved in meaningful work, all of which translated to increased self
esteem. The theoretical and experiential literature depicts this outcome and according to Trainor et al. (1985) cited in Pape (1988), "participation is the key way of fulfilling the goal that people with severe mental health problems lead rich and fulfilling lives in the community, with a sense of belonging, acceptance, and inclusion in community life" (p. 2). Throughout the experiences of the participants can be seen an increased sense of power and respect attributed in part to board and committee work. For many of the participants there was this sense of lack in their lives before they became involved with board and committee work. It was as if the board and committee work allowed them to heal certain parts of themselves as well as fulfill the need for power and control in their lives. The participants offered a deeper understanding of the self-esteem issue and even suggested that there is a danger in board and committees completely subsuming one's sense of self. Overall, the experience of increased self-esteem due to involvement on boards and committees is congruent with the literature.

Al-Issa's (1994) research of participation rates on boards and committees and other mental health services by consumers were related to variables such as coercion and equality. This portrayal is similar to that described by the participants. In particular, high participation was found among consumers who felt listened to, could challenge and negotiate, who sensed equality, and earned recognition for their efforts. These factors were all present among the accounts of the participants in the study, perhaps contributing to their continued involvement. Nonetheless, the variables associated with low participation such as lack of information, coercion, and lacking power were also present in the experience of the participants. In the current study it appeared that the degree of powerlessness in the stories of the participants was related to their energy and commitment to staying involved, in that, those who felt like they had little control often talked about leaving board and committee work more often then
those who felt more in control. Given that all of the participants selected for the study were still involved with board and committee work, it would be interesting to look at the variables associated with participation rates in consumers who have left board and committee work.

The experience of frustration was a common theme among the participants and usually centered around the slow process of board and committee work. Similarly, Valentine and Capponi (1989) state that consumers may experience role strain because of the clash between the slow pace of bureaucratic structures and their need to produce change. Consumer board members have a direct need for mental health services themselves. They may also want to help other consumers and to correct injustices in the mental health field. Subsequently, the slow process of change may be frustrating and unbearable. Furthermore, participants were frustrated with the group dynamics at times. Al-Issa (1994) and Church and Capponi (1991) addressed group dynamics as an area that consumers needed training in before entering boards and committees. Their goal is to help consumers to have more options such as a communication skills or awareness of stress releasers in order to better be able to cope with it. Nonetheless, none of the participants involved with the study spoke of prior training and preparation. Overall, frustration was not mentioned in the theoretical literature, however, the event’s which the participants attributed to causing frustration were cited as barriers to consumer involvement on boards and committees.

A feeling of being separate or different from non-consumer board and committee members emerged in the participants’ accounts. Participants described the experience as being distinct or feeling a sense of otherness. In light of the mental health system’s history of exclusionary, controlling, custodial, and stigmatizing practices (Toews & Barnes, 1982), this finding is not unusual. The gap between consumers and non-consumers is real although some of the participants felt board and committee work helps to bridge the gap. Nevertheless,
Valentine and Capponi (1989) assert that professionals may experience role strain and have difficulty in treating consumers as equals. Therefore, the experiences of consumers in feeling separate or different fit within the context of the mental health system. In fact, the Board Sensitization package produced by Capponi (1991) tries to bridge the gap between the two stakeholder groups in terms of this area.

A further area of separation experienced by the participants was that of disconnection with consumers as a whole. Some of the participants had lost friendships with other consumers because of their role as board and committee representatives while others feared co-optation by the system. Literature focusing on the experience of separation from other consumers and co-optation is non-existent. There is recognition of the institutionalizing effects of the mental health system (Braun & Kochansky, 1991), but not on the danger on becoming institutionalized or co-opted through board and committee work in the mental health field. The notion of co-optation is a fear that in trying to replace and change the current mental health system, the consumers may get caught up and forget about the people they are supposed to represent. In the end the fear is there that instead of changing the mental health system they becomes like it. This unique perspective was not portrayed in the literature.

Upon first joining boards and committees, the participants felt uncomfortable or intimidated by other members as well as by their role and responsibilities. This is echoed by White (1989) who felt uneasy, uncomfortable, and lacked confidence in her abilities when first joined a committee. The feelings of intimidation was also present for another consumer as reported in Capponi (1991), "every time I open my mouth I feel like I'm putting my foot in it. And I find it very hard to understand the jargon they use. When I say that they look at me like I'm a dummy" (p. 16). It appears that acculturation to board and committee work
involves discomfort and fear, however, White (1989) suggests that a buddy system with another board member could help mediate this at the beginning of one’s tenure on the board or committee. The participants in this study shared the common experience of being among the first consumer representatives on the boards on which they serve. This may have contributed to their sense of discomfort. In short, there are parallels between the participants’ experiences and the literature on the discomfort experienced upon first entering boards and committees.

The participants in the current study experienced stress and exhaustion as board and committee representatives. Certain aspects of board process, group dynamics, and having to speak in front of people were experienced as stressful. As White (1989) explains, consumers speaking about their experiences within the mental health system can be emotionally draining. White (1989) asserts that consumers speak from personal experiences which can be draining compared to speaking from the safety of academia. Furthermore, many of the participants reported feeling exhausted or burned out from having too many responsibilities and not enough time. Long (cited in Carling, 1993) states that too few consumers are spread too thin and lack preparation and support; thus burnout is an issue. Most of the literature written by consumers addresses the issues of stress and exhaustion as part of the experiences of consumers on board and committees.

As a counterpart to the experience of stress and exhaustion among the participants came the experience of coping with stress, pressure, and frustration. The means of coping reported by the participants included altering one’s thoughts, having outside support, humour, and even using substances such as alcohol and prescription drugs. The documents and research on consumer participation on boards and committees do not address the experience of coping with stress, pressure, and frustration, however, they do recognize stress and exhaustion as
part of these experiences. After exploring the positive and negative experiences of consumers on boards and committees it is understandable that stress would be part of this.

Among the participants there was a recognition of the lack of consumers who are involved with boards and committees. Although the suggestions for facilitating consumer involvement were not common among the participants, their ideas are useful to review. Pape (1988) and White (1989) acknowledge the lack of consumers on boards and committee and Valentine and Capponi (1989) attribute this in part to the incongruency between organizational values and actual practice. For example, an organization may say consumer involvement is important, however, in actual practice they may only have one consumer position on their board or committee. Despite this fact, the participants in the study attributed the shortage to a lack of interest among consumers in fulfilling board and committee roles. As one participant put forward, it is assumed that because consumers have mental health issues, they will naturally want to be involved. This assumption is reiterated by Charles and Demaio (1993) in looking at lay participation in health care decision-making. The government has assumed that people will be interested in tackling health care issues however, in actuality they may not wish to take on this responsibility. Al-Issa et al. (1993c) addressed this issue in their Consumer Development Project. They designed a board workshop for consumers to peak consumers' interest in being involved with boards and committees.

Another view on the shortage of consumers offered by the participants was that of conflict of interest. By becoming a board or committee member they could be in the position of both service provider and recipient. The fear lies in that by becoming a service provider they could jeopardize the services they receive, for example, disagreeing with professionals on the board who deliver their health care. The literature does not directly address this as a barrier to involvement although Valentine and Capponi (1989) indicate role strain is a
problem for consumers and conflict of interest can be viewed in terms of role strain.

The other reason attributed to the shortage of consumers by participants was that of failure of consumers themselves in involving others. Some of the participants felt they either didn’t have enough time, enjoyed their elite position too much, or couldn’t find suitable replacements, and this led to a shortage of consumers. In terms of the literature, nothing is mentioned regarding consumers’ responsibility in involving other consumers. Overall, a number of reasons have been put forward to explain the shortage of consumers on boards and committees, some of which is recorded in the literature, and others that are unique to the participants in the study.

In the participants’ accounts there was a recognition of the value of advanced preparation and training before entering board and committee work, however, not one of the participants actually received any. The participants suggested the areas of need are in communication skills and understanding board process. Numerous researchers have articulated this view (Al-Issa et al., 1993; Capponi, 1991; Church & Capponi, 1991). Al-Issa et al. (1993) and Church and Capponi (1991) developed training and preparation packages for consumers in entering board and committee work. Specifically, Al-Issa et al. (1993) developed an orientation manual for consumers to keep with them including a glossary of terms. Church and Capponi (1991) on the other hand, developed the Leadership Facilitation program which is comprised of workshops which prepare consumers for involvement on boards and committee as well as advocacy work in general. Overall, it appears that both the participants in the study and the literature agree that advanced training and preparation is useful in facilitating consumer involvement on boards and committees.

The experiences of Jory as a participant on a committee comprised only of consumers are noteworthy. The literature did not suggest her experiences would deviate from that of
consumers on mixed boards and committees, she was included in the research. However, she did not share all of the experiences with the other participants. In particular, Jory did not experience a power differential between consumers and non-consumers, being assertive as a female participant, feeling separate or different, feeling uncomfortable upon first entering her committee, and having to cope with stress and exhaustion. Not experiencing a power differential with non-consumers is expected given that there were no non-consumers on her committee. Furthermore, one would expect her to not feel separate or different in an all-consumer committee as they are all part of the same stakeholder group. In addition, one would assume her discomfort upon first entering the committee would be reduced in comparison with other participants because of the equal status of her members and their camaraderie. The absence of the experience of being assertive for female participants and not coping with stress and exhaustion is open to speculation and could be due to her all-consumer committee or other unknown variables. Overall, Jory's experiences were somewhat unique among the participants and it is hypothesized that her all-consumer committee may have been a contributing factor.

In summary, the findings indicate the gaps inherent in the literature in terms of the experiences of the participants on boards and committees. The gaps appear in the following areas: background experiences and skills brought to boards and committees by consumers, recruitment methods, "purpose" versus the feeling of contribution and helping others, assertiveness for female participants, being separate or distinct from other professionals, as well as the fear of co-optation, means of coping with stress, ideas for facilitating participation on boards and committees utilizing consumers themselves, and a examination of all consumer committees. Nonetheless, there are numerous areas of congruency among the experiences of the participants and the literature: the difficulty in representing the views of
all consumers, role confusion, lack of support and power differential as problematic, increase in social contact and financial means through board and committee work, empowerment and increased self esteem, feeling uncomfortable when first joining, stress and exhaustion, and the need for advanced preparation and training. Furthermore, although the literature debates that whether consumer involvement is about providing better services to others or empowerment, the participants are clear in their ideas. They see their involvement as helping other consumers and creating a better mental health system. Furthermore, they would maintain that empowerment comes through opportunities and it is something they do for themselves, not something that is imposed on them by others. Overall, the findings indicate that the experiences of the participants in this study deviate as well as corroborate some of the perspectives offered in the literature. On the whole, a deeper and richer understanding of consumer involvement has emerged.

**Personal Meanings**

In the initial stages of the study I revealed my personal assumptions and experiences as a mental health worker that helped fuel the desire to study consumer involvement on boards and committees. In addition to increasing awareness and understanding of the experiences of consumers as board and committee members in the mental health field, I have also grown as a professional by being involved with this study.

The emergence of the themes was an interesting process for me. I found myself holding onto the theme of "purpose" having been largely influenced by the literature review. I realized that this theme didn’t fit with the experiences of the participants, and that "purpose" was a term from the literature, found in reports that needed to justify consumer involvement. For the participants this justification was not needed, through their eyes they had a right to be there and wanted to help make it better for others. I became aware that I was trying to
make sense or meaning out of their experiences through the filters of the literature and my
own experiences but what I really needed to do was just to sit back and let the meanings
emerge from the sentences of the participants. Once I experienced this new awareness I was
better able to hear the experiences of the participants through the distractions of the literature
and my own experiences. In the end I feel I was successful because after finishing writing
the themes I reviewed the literature and was surprised at the similarities. It was as if I had
forgotten the literature review I had written myself.

Throughout the interviews with the participants and the data analysis, I continually
processed my relationship to the study and to the mental health field as a whole. During this
time I left my position as a mental health worker and became more on the fringe of mental
health issues as an employment counsellor. The change in the positions provided me with a
much better advantage point to view and analyse the data as I was no longer part of a direct
mental health stakeholder group. One of my realizations was that by virtue of working
directly in the mental health system I was institutionalized to think according to a certain
pattern and it was only by stepping out of this culture that I could see things differently. I
was better able to see the weaknesses as well as the strengths inherent in different mental
health programs and the system as a whole. In listening to the participants' stories I started
to think differently about was the role of mental health worker and the issues of
empowerment and equality. As a mental health worker I was taught that consumers rely
heavily on the services we provide them. Nonetheless, through the eyes of the participants I
began to appreciate the strength of the consumer movement and the determination of the
community of people with mental illness in altering the power structures. I realized that the
consumer movement is just that, a movement run by consumers. While employed as a mental
health worker I felt too threatened to think my services weren’t as important as I had been
led to believe. However, I began to redefine my role in relation to the consumer movement and started to see myself as a resource and support person.

In the beginning of the study I had debated the notions of empowerment and equality. Through the eyes of the participants I have a new appreciation for both of these. Empowerment is about growth and self esteem, it is something one does for oneself. Support and assistance from others is important yet it is essentially our very own journey. I looked at myself in terms of equality, what did it mean and how did it look. I realized it is about respect and seeing each person in terms of our common humanity. I was also honest with myself in that despite how equal we want to pretend things are between consumers and non-consumers they simply are not, stereotypes, discrimination, health issues, and differing economic status still exist. However, what I do see is a bridge that is being built by a number of people who know there has to be a better way. I realized that not only do professionals have to learn but so do consumers as well if we are ever to bridge the gap. The relationships are slowly being redefined.

As I stand back to look at the study, the experiences of consumers, and the literature, I am somewhat astonished that mental health organizations sometimes need a government mandate to include consumers in the decision-making process. If the situation is paralleled to women’s or gay organizations it is not even questioned whether these stakeholders should be involved in providing services. In my estimation two forces remain that prevent a similar scenario in the mental health field. One, stereotypes are held regarding consumers not being able to make rational decisions and act as contributing members in society, and two, the unwillingness of the gatekeepers in the mental health system to relinquish power to consumers. Nonetheless, there are consumers that are trying to organize their community with increasing success. Furthermore, there is a growing number of mental health workers
that are supporting them in these efforts.

My perceptions of the data are affected by my current role as an employment counsellor. In working with social assistance recipients returning to work, I began to notice parallels between the themes that were emerging in the data and the needs of the individuals with whom I was working. When returning to work after long-term unemployment there is a recognition for the need of supports, for example, training, as well as a recognition of potential barriers like one’s past work history. Consumer participation can be seen in the same light, certain supports are necessary in its facilitation, such as training, financial, and emotional assistance. Furthermore, certain barriers can alter involvement, for example, the power differential, feeling intimidated, as well as stereotypes. The outcomes of paid employment such as empowerment and increased self esteem can be paralleled to board and committee work outcomes. Frustration, stress, developing friendships, and group dynamics are also outcomes of employment as well as board and committee work. In addition, work environments need to be free of harassment and to have vehicles in place for assuring harassment is dealt with should it arise. Board and committee work also needs a similar environment in order to maximize the usefulness of all stakeholder groups. In looking at facilitating board and committee participation I realized that the skills needed for board and committee work are not all that different from paid employment. This realization helped when thinking about the implications of this study and the type of training the participants might need in order to facilitate their movement onto boards and committees.

The insight that has led to the most growth for me is the greater awareness that we (consumers and non-consumers) fundamentally need and want the same things out of life. Although I, like other mental health professionals, paid lip service to this concept I never had a full understanding of it. Deep within the stories of all of the participants was a sense of
lack, a longing for something that was missing. It seemed board and committee work helped the participants to explore and rediscover themselves and to fill the sense of emptiness they carried. In the end I believe they felt a sense of meaningful contribution, of purpose and belonging that are basic human needs.

On the whole I have developed a deeper, richer, and greater understanding of the experiences of consumers on boards and committees, the mental health system, the consumer movement, and the role of mental health professionals. I feel that the real struggle for consumers is not to be seated at board and committee level, rather it is to be heard and hold positions of power.

**Implications for Practice**

The purpose of this phenomenological study was to explore and describe the experiences of consumers on boards and committees within the mental health field. The findings of the study suggest certain implications for the facilitation of consumer participation and further research.

**Facilitation of Consumer Involvement**

Throughout their accounts, the participants suggested a need for more consumers on boards and committees. Their experiences affirmed that there is little justification in building a system of mental health care without including consumers in the decision-making process. The British Columbia Mental Health Services Division has mandated that 1/3 of all members on mental health boards and committee be consumers and/or their family members (Pape, 1992b). There is an increasing demand for consumer participants. In this study the participants addressed a number of issues in the facilitation of consumers on boards and committees. Four main areas in relation to facilitation will be discussed, the recruitment process, role and responsibilities of consumer representatives, supports, and advanced
Recruitment:

1. Given the shortage of consumers on boards and committees, measures taken to interest consumers in assuming a participatory role may be useful. Board workshops as outlined by Al-Issa et al. (1993c) aim to increase interest and awareness of board and committee work among consumers therefore widespread implementation of the board workshops could help address the shortage in consumers. Furthermore, the findings of this study help point to areas that are positive and potential benefits to consumers through involvement. These benefits could be illuminated in the board workshops. Nonetheless, it should not be assumed that board and committee work is naturally of interest to consumers because of their own mental health history.

Roles and Responsibilities:

1. The participants in the study reported a variety of roles and responsibilities as consumer representatives. They experienced difficulty in fulfilling their roles and responsibilities due to a variety of expectations on them such as remaining loyal to consumers, representing a specific mental health agency, as well as portraying the needs of all consumers. Furthermore, when first joining their respective board or committee, the participants were unclear as to their role and responsibilities. Clarification of the roles of board and committee members would be beneficial to consumer members. The responsibilities of the consumer members should be clear and realistic, and consumer should not be expected to represent the needs of all consumers.

2. Some of the participants were uncomfortable being expected to share their sad story as well as speaking in the first person. Furthermore, continually recounting one's mental health history was stressful and draining. Some of the participants suggested that instead of focusing
on their disabilities, the role of consumer representative should take into account their
abilities. It would be useful to consider the skills and abilities of each consumer member
outside of their experience with mental illness, for example accounting or fundraising ability.

3. The participants reported that the power differential between them and the mental health
professionals adversely affected their participation. The broad implementation of the ideas
suggested in Capponi's (1991) Board Sensitization package regarding board process and role
change for non-consumers could help address the power differential. For example, the
document suggests informal settings for meetings, simplification of language and documents,
as well as a reduction of exclusionary conversation by non-consumers that serves to heighten
the differences between the themselves and consumers.

Supports:

1. Survey consumers who have quit board and committee work as well as consumers that are
currently participating in order to validate the necessary supports for participation on boards
and committees. The survey could also include consumers who are considering involvement.

2. Given the feelings of discomfort and intimidation upon first joining boards and committees
reported by the participants in the study, it may be useful to provide additional supports for
consumers at an early stage of participation. The support provided could be dependent upon
the needs of each individual. The participants in the study suggested supports such as other
consumers on the board and committee, access to an outside resource person, and prior
training to ease the intimidation and discomfort.

3. Among the accounts of the participants emerged the experience of separateness and a
power differential between them and non-consumers. These experiences were often linked
with negative emotions and a hesitancy to participate. Boards and committees should make
every effort to provide a safe, non-discriminatory work environment that is open minded so as to help facilitate involvement.

Training and Preparation:

1. The participants in the study felt overwhelmed and ill prepared for their role on boards and committees. Furthermore, the participants reported frustration and feelings of disempowerment at their inability to fulfil certain responsibilities, such as not being able to understand board documents and lacking specific skills. A number of the participants indicated that a training program prior to joining may have helped ready them for their role. Advanced preparation may also serve to alleviate the negative experiences of frustration and disempowerment. Specifically, the implementation of the Leadership Facilitation Program (Church & Capponi, 1991), and its operation by a mental health consumer appears to be a useful training program for consumers. The addition of the Board Manual created by Al-Issa et al. (1993b) in conjunction with the training program would also be helpful to consumers. In addition to the information outlined in Church and Capponi (1991) and Al-Issa et al. (1993b) additional workshops focusing on stress and coping as well as assertiveness, and conflict resolution skills could be beneficial to participating consumers.

2. The participants experienced a power differential between consumers and non-consumers on board and committees which resulted in negative feelings and unequal participation. It is important to have a Chairperson for each board and committee who is aware and sensitive of the dynamics between these two stakeholder groups. Specialized training for the Chairperson that focuses on becoming sensitive to consumer needs and maintaining a balance of power among the stakeholder groups would be useful.

3. The addition of information regarding consumer involvement and the consumer movement to educational programs for mental health workers could be instrumental in altering the
power differential between consumers and non-consumers. Furthermore, this information should be part of the training of any new staff in mental health organizations in order to promote the facilitation of consumer participation.

Further Research

This study has provided insight into the experiences of consumers on boards and committees in the mental health field. In light of these findings, areas for further study are suggested:

1. An exploration of the experiences of consumers on all-consumer boards and committees could be compared and contrasted to the experiences of participants in this study. Jory was the only individual in this study who participated on a strictly consumer committee. A number of her experiences were dissimilar with the experiences of the other participants.

2. A study of the experiences of consumers who started board and committee work but stopped within a year could shed light on a variety of issues in the area of consumer participation. It might be useful to explore their background experiences and the presence of factors associated with low participation mentioned in Al-Issa's (1994) study such as coercion and lacking power.

3. A study of the perspectives of non-consumers who participate with mental health consumers in identifying their concerns, and perceived barriers to consumer participation could help increase the information available on consumer involvement.

4. A study and evaluation of the development of Regional Health Boards as devised under New Directions (Ministry of Health and Ministry Responsible for Seniors, 1993) in terms of outcomes and ability of stakeholders to collaborate would provide interesting data.

5. The British Columbia Mental Health Services Division (Pape, 1992b) has mandated 1/3 consumer membership on boards and committees. However, there is no mention of an.
evaluation of this mandate among mental health associations and organizations. An evaluation of consumer participation on boards and committees would enable further understanding of the practices of boards and committees in involving consumers. Much of the literature in the area of consumer participation is largely theoretical therefore it would be useful to have a survey of existing practices across Canada.

In addition, there are two recommendations regarding the usage and facilitation of research. These recommendations are based on the researcher's inability to attain information and literature on consumer participation as some of the field research is unpublished. Furthermore, articles that appear on consumer participation are often in journals with limited access and the articles are often theoretical rather than research oriented.

1. Widespread distribution and publication of field research and documents relating to consumer participation among mental health programs and agencies.

2. Submission of field research to journals and periodicals such as the Psychosocial Rehabilitation Journal.

3. The provision of a research support person through a mental health agency or government to assist lay workers and consumers to produce research related to a variety of mental health issues such as consumer development.

Conclusion

The experiences of consumers as board and committee members within the mental health field was the focus of this phenomenological study. Nine consumers were interviewed who were currently participating on either a mental health board or committee and had been for over one year. The collection of the data and analysis occurred simultaneously until all of the participants had been interviewed twice. From the first interviews with the participants, tentative themes were developed and later verified and elaborated on in the second interview.
The final analysis produced eight themes and four subthemes that were common to eight of the nine participants.

A description of the experiences of consumers illuminates the meaning of their participation on boards and committees. This knowledge sheds light on the facilitation of consumer involvement and the consumer movement as a whole. This study does not assume that the picture of consumer participation as painted by the participants encompasses the experiences of all consumers on boards and committees. The experiences of the participants do not provide a definitive understanding of consumer involvement, rather, it has provided a glimpse into the world of boards and committees in the mental health system. This study is ultimately a reflection of consumers continuing journey for respect, power, and a meaningful role in society.
References


Appendix A

Personal Assumptions
Personal Assumptions

The lived experiences of consumers as board and committee members within the mental health system.

The following list is a set of personal assumptions held by the researcher which were brought to the study. The assumptions include an outline of the themes I believed would emerge from the consumer’s accounts of participating as committee or board member in the mental health field.

1. That people with a mental illness are capable of describing their experiences on boards and committees.

2. That people with a mental illness have the capability to act as committee or board member in the mental health system.

3. That the power differential between consumers and mental health professionals still remain in favour of the professionals and may act as a barrier to consumer participation.

4. That consumer participation on boards and committees is a democratic right of consumers and serves to enrich the services available in the mental health system.

5. That the consumers who are currently participating on boards and committees will reveal experiences of burn out due to the shortage of consumers who are take on this role.

6. That consumers will describe experiences of fulfilment and empowerment due to their role as committee or board member.

7. That consumer involvement is more often talked about in mental health agencies that actually put into practice.

8. That the topic of consumer involvement on boards and committees has not been fully explored as of yet and needs to be if consumer involvement is to be understood and facilitated.

9. That the motivation for consumers to become involved on boards and committees may be fuelled by their anger at past treatment by the mental health system and society in general.

10. That this study will promote the researcher’s personal growth as a mental health worker and future counsellor within the mental health field.
Appendix B

Advertisement for Recruitment of Participants
Appendix C

Letter of Information to Participants
Appendix D

Letter to Key Informants
Appendix E

Consent Form
Appendix F

Geographic Location of the Participants
Geographic Location

**Vancouver Region**

Richmond
Vancouver

**Fraser Region**

Abbotsford
Burnaby
Chilliwack
Coquitlam
Maple Ridge
Port Coquitlam
Surrey
White Rock

**Rocky Mountain / Kootenay Region**

Cranbrook
Creston
Nelson
Trail
Appendix G

Sample Questions
Sample Questions

The lived experiences of consumers as board and committee members within the mental health system.

The following is a sample of trigger questions and probes that will be used in the interviews in order to elicit information. The specific wording may vary slightly within the interviews, however, the overall purpose of the questions will remain the same.

1. Can you recall a time when you were not involved as a committee/board member? Can you tell me the story of how you came to be involved? What has happened for you since your involvement?

2. You mentioned feeling ________ in your experiences as a board member. I am wondering if you could give me a specific example of when you felt ________ as a board or committee member?

3. In relation to the above question: Could you describe a time when you didn’t feel ________ as a board or committee member?

4. What would you miss most if you couldn’t participate on boards and committees anymore?

5. Some of the other consumers interviewed have mentioned _______________________ as part of their experiences, can you relate to this?

6. Further probes may be used to clarify certain experiences and to facilitate the sharing of additional information such as:

   a) Could you elaborate on that experience for me please?
   b) I am not sure I understand, you feel . . . ?
   c) How did that experience make you feel?

7. Is there anything else you would like to add to you list of experiences?