PARTICIPATION AND MEANING IN COMMUNITY:

FROM THE STANDPOINT OF CONSUMERS WHO RESIDE IN SUPPORTED HOUSING

by

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Abstract

This study was carried out within a qualitative research framework. A purposeful sample was utilised with eight individuals in a focus group format, to gather information about their experiences. All eight individuals in the study experienced some form of a psychiatric disability, and lived in supported housing. The purpose of the study was to explore how people with psychiatric disabilities who live in supported housing define, and participate in community. A constant comparative analysis was used during the research, based on structuralist and standpoint theory. This resulted in six major issues/themes: The benefits and importance of the consumer/mental health community; ideas pertaining to community change; positives of support and subsidies; changes needed to support; barriers to involvement in the geographic community; losses. The study provided opportunities for consumers to explore their perceptions of community, and dialogue as a group. Some insight with respect to altering social work practice was developed through the findings. Social workers and other mental health professionals are required to acknowledge the strengths and resources of consumers, and cannot neglect a focus on community change to provide holistic support to individuals who reside in supported housing.

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Introduction

My individual experience in the field of mental health began in 1991 at Riverview Hospital (a tertiary care facility in B.C.) when I volunteered in a one to one capacity with a long term resident. I have been employed as a social worker since 1994 and have an array of experiences in diverse settings within institutions and the community. During these experiences, the most notable aspect of my positions was the power that professionals were granted over people who experienced a psychiatric disability (Consumers/survivors). As a mental health professional, one has substantial power with respect to obtaining information and making decisions in a consumer's life. The oppressive nature of the formal mental health system is unavoidable since services continue to rely on the input of professionals when treatment and delivery and planning of services takes place. The oppressive nature of the formal systems continues to be reduced with the involvement of consumers and their families.

When one's problems are taken out of the context of their environment, then issues are individualised and individuals are blamed for their own difficulties. In clinical practice, people with mental illness are treated out of their homes and labelled as patients (Wilson 1996), and most direct contact occurs in a controlled environment such as a hospital, mental health centre, or perhaps some other resource. On many occasions, psychotherapy and pharmacotherapy as methods of treatment, focus on the individual exclusive of their environment. Subsequently, after sessions or hospitalisations, individuals return home where perhaps some basic needs are not met. Often, people return to communities where they have few friends, no opportunities for employment, little financial resources, and neighbourhoods that are overtly hostile. It becomes very clear during practice, that focus on the community should be a priority to enable individuals with psychiatric disabilities to maintain well being.

> The basic belief of the community integration movement is that all people, including people with disability labels, have a right to full community participation and membership. Moreover, the movement maintains that this goal will not be achieved primarily through professional services, but rather through peer support and self-help, as

well as through physical, vocational, and social integration into the mainstream community activities, housing, jobs, and relationships with non-disabled peers (Carling 1995 pg.21)

Furthermore, research in the field of mental health has been carried out by professionals using quantitative methods for the most part, fitting consumers into predetermined hypothesis. There is a significant gap in the research with consumers. What is sadly lacking is research from the standpoint of the people who experience psychiatric disabilities, such as qualitative studies to gain information about the life experiences of people with psychiatric disabilities who reside in the community.

Historically, mental health professionals have focused on individuals with psychiatric disabilities as being ill and as having deficits. In Canada, prior to the 1960's, individuals who experienced a mental illness were institutionalised in large psychiatric hospitals. In 1964 the Royal Commission on Health Services indicated to the provinces in Canada, that people receiving care in mental institutions should be moved to the community and general hospitals. As a result, the capacity of mental hospitals decreased from 47,633 to 15,011 during the period 1960-1976 (Wasylenki et al 1992). This decrease in services was not accompanied by a proportionate increase in acute care beds in the general hospitals across the country. People with significant psychiatric disabilities were now transferred to geographical communities for services.

In British Columbia, there has been an exodus of people with psychiatric disabilities from institutions to the surrounding geographic community in the last three decades. This movement has tested their vigilance with respect to facing opposition from other established community members and institutions. Consumers now are being encouraged to tell their stories about experiences in treatment and how institutional oppression has created many barriers to their success (Carling 1993). Researchers have also had difficulty in situating consumers in the community with respect to their studies. Little research has been completed that focuses on the effect that communities have on people with mental illness and what interventions may be required at the community level. Recently, some professionals have strived to situate consumers

in the geographic community, but consumers' perceptions of communities that they belong to may be different.

With the move to community treatment, an increased awareness and research into the environmental influences on people who experience psychiatric disabilities began to occur (Bachrach 1993). In the 1980's and 1990's, treatment for people with psychiatric disabilities began to shift from a predominant medical model approach where medications and physicians dictated treatment to, a biopsychosocial approach (Bachrach 1993). Within the approach, an individual and their family, along with many other disciplines in health, became a team in approaching treatment and support with respect to managing a psychiatric disability. This shift in philosophy towards self determination for people with psychiatric disabilities occurred in conjunction with many other social movements in North America such as the development of self help and the demedicalisation of self care with respect to terminal illness (Towers 1994). This philosophical shift is labelled as *consumerism,* and individuals who were provided with public sector services were labelled as consumers. In Canada, many people with psychiatric disabilities describe themselves as consumers of mental health services, and some identify themselves as survivors of mental health services.

The notion of consumerism challenges the hierarchy in mental health services across Canada. It challenges the authority and paternalistic dominance of physicians and other mental health professionals that work with people who experience psychiatric disabilities (Towers 1994). Consumers/survivors are currently being asked to participate in planning mental health services, and to be integral in the treatment process, although this is a recent phenomenon. People that experience psychiatric disabilities are also being relied on to advocate for housing and to provide education to the general community and professionals within the mental health community. Within the context of consumerism, people with psychiatric disabilities would be able to identify changes needed that would benefit themselves. People who experience psychiatric disabilities and oppression have a reality very different from professionals, thus the goals and priorities that are set would be markedly different that those identified by mental health

workers. I believe that professionals have more access to participate in research, and goals for people with psychiatric disabilities have been identified and set by researchers.

Individuals with psychiatric disabilities have gained supportive housing through advocacy which has promoted independence and improved the quality of life for people who had previously been housed in institutions. In a supported housing model, people with disabilities are able to choose their housing, choose their support, and have a residence which is integrated into geographical communities. However, from my experience, consumers are residents of the geographical community but they are generally not active participants. In the last decade, people with psychiatric disabilities have started a grassroots movement in British Columbia, and have taken social action to reduce oppression through education and lobbying to the government. However, professionals need to change their practice from a model where individuals are the focus to one where community change is the primary objective if we hope to advocate for, and empower individuals.

Through my personal and professional experience, it seems that people with psychiatric disabilities are supported primarily by professionals and peers. The formal mental health system has numerous flaws but it is moderately effective in providing reactive treatments for people with mental illness, although continues to be oppressive. Individuals who have suffered from oppression through *treatment* from professionals and the community have unique experiences that have not been well documented as Jayne Melville Whyte (1996) states, "In many cases oppression is an unplanned side effect in the treatment of mental illness. Professionals seem unaware of their power and privilege and how their authority is perceived" (pg. 22).

Individuals with psychiatric disabilities will face systemic discrimination and oppression in the community when they return home from hospital. People with chronic psychiatric disabilities have few friends who are not consumers, they are rarely employed, and have virtually no voice in the geographical community. All people have value and can offer their unique skills to a community if provided with the opportunity to participate. I feel that consumers can deconstruct oppressive institutions such as the hospital and formal mental health clinics if there

is a forum for exchanging ideas. People with psychiatric disabilities have solutions to their own barriers but require support and facilitation to participate in community action.

An exploratory qualitative study provided an arena for consumers to talk about their experiences in the community and identify areas for themselves and professionals to focus on for change. Practice by mental health professionals should be evaluated within the framework that consumers identify, thus the information learned from people's experience should guide future practice. The goal of this study is to explore how consumers who reside in supported housing define, and participate in community.

This study is separated into six chapters including the introduction. In chapter two, the literature will be reviewed. The literature will be discuss the areas of supported housing; structuralist theory; consumer's struggle for valued roles; evolving professional intervention; participation; social supports and belonging. In chapter three the methodology of the study will be outlined. Standpoint theory will be explored in regards to the conceptual foundation of this study and chosen methodology. This section will focus on the relevant techniques used to obtain information for the study and the method which was used to analyse the data. The merits and disadvantages of focus groups will also be dialogued. Chapter four contains the findings of the study derived from the focus groups. The findings are discussed from the perspective of the participants, along with my interpretation of the data. Chapter five contains the discussion of the findings. The findings are related to the literature, and connected to implications for social work practice. The limitations of the study are also explored in this section.

CHAPTER TWO

LITERATURE REVIEW

Few qualitative studies have been completed with consumers/survivors in Canada and no studies carried out in British Columbia were found in the literature search. One of the main pieces of research that guided this study was completed by Lord et al. (1987) where they used a qualitative framework to explore the needs of consumers/survivors from the perspective of the participants. They found four main areas that consumers perceived was essential for their well being in the community. Firstly, participants in the study needed to belong to the community through gainful employment or other meaningful activity. Secondly, they emphasised the importance of professional supports, but also discussed the negative impact that formal supports have in the lives of consumers/survivors. Thirdly, the need for friends and other informal supports was explored as well as the advantages of self help. Lastly, the participants indicated their struggle for an identity in the communities where they resided, and explained how their disabilities affected their self perception. These findings guided the review of the literature, and there was also a focus on research around supported housing since the participants in this current project all reside in some form of supported housing.

SUPPORTED HOUSING

Supported housing is the product of an evolution of residential options that have been developed for people with psychiatric disabilities in communities in Canada over the last thirty years. The downsizing of major psychiatric facilities in the 1960's significantly affected a change in thinking about individuals with psychiatric disabilities (Bachrach 1993). There was a shift from a strict medical service model, to a more psychosocial framework that looked at societal factors as having an effect on mental wellness. Between 1960 and 1976 in Canada, 47633 beds in psychiatric institutions were reduced down to 15011 (Wasylenki et al.1992). The size of institutions was reduced and the form of authoritarian care within residual or custodial

models of shelter and treatment began to have little relevance for moving to the community and subsequent integration with the general population (Aubrey et al. 1995). A process that took approximately 16 years forced drastic changes in mental health policy, and the individuals that were most profoundly affected were those with serious psychiatric disabilities who had previously been housed indefinitely in institutions

There was a drastic need for safe and affordable housing for consumers in the 1970's, and this trend continued into the 1990's. British Columbia's Strategic Mental Health Plan (1993) identified housing as a priority. Types of housing in the community needed to be developed for different needs, levels of support, and for different sub-groups such as the elderly or single parent families. Mechanic (1989) indicated that a broad spectrum of housing is essential for the transition from institutions, such as hospital, to community integration.

Housing for people with psychiatric disabilities gained importance after the onset of deinstitutionalization in the 1960's. People were being transferred to communities to increase normalisation, but the development of many resources, including housing, was slow (Mechanic & Rochefort 1990). With the downsizing of psychiatric hospitals, the responsibility for treatment and support was shifted to the unprepared community causing a fragmentation of services (Wilson 1996). Resources for individuals who required some form of supported arrangement were scarce. Suites for independent living were the preferred choice for many individuals leaving the hospital, and continues to be preferred today. However, many individuals require some form of support to facilitate community living, and in most cases this was delivered by the government (Carling 1993). People with psychiatric disabilities experience many barriers to success in the community such as stigma, poverty, and the effects of the disability. Supportive housing as a model was devised to ease the integration into community for consumers with significant disabilities through developing safe and affordable housing with supports if needed.

While there was focus on the integration of consumers into geographic communities through the downsizing of major institutions, communities were unprepared, uninvolved and uneducated about individuals who experience psychiatric disabilities. The community is often

resistant when a continuum of suitable housing options is explored or established (Mechanic 1989). More recently, Carling (1995) stated that. "At a community level, negative attitudes have become structured into social patterns of segregation, discrimination, and inadequate support for mental health services (particularly alternatives to institutions)". Within the context of residency in geographic communities in Ontario, Aubry et al. (1995) found that individuals with severe psychiatric disabilities would be socially stigmatised more than individuals with lesser disabilities. People in the community were found to be uneducated about mental illness but also perceived that housing for consumers would lower the property values in their neighbourhoods (Milstein 1988).

For the purpose of this project it is important to define supported housing as this is the residential milieu that the participants were drawn from. Carling (1995) identified three principles that are required for supportive housing;

1. Consumers have their choice of housing

2. Housing is integrated into the geographic community

3. Supports are chosen by the consumer

Consumers with psychiatric disabilities have gained supportive housing through advocacy (Wilson 1996) which has promoted independence and improved quality of life for people who had previously been housed in institutions (McCarthy & Nelson 1993; Carling 1995). The housing required for individuals with psychiatric disabilities also needs to be flexible and available for individuals who are likely to experience an acute crisis on occasion.

> The housing should meet personal subjective expectation. It should be normal for the community and social environment and meet community health standards. It should be permanent or available for as long as the individual can maintain tenancy, and it should be protected in times of crisis and hospitalisation. (Sohng 1996) (137).

A conceptual shift has occurred in the last two decades whereby clients of sheltered housing are now being perceived as tenants of supported housing. They are viewed as

community members who were not only residing in places for treatment, but also living in these residences as permanent homes (Ridgeway & Zipple 1990). While supported housing was being developed, many different residential options began to emerge, such as co-operatives, room and boards, specialised group homes, and supervised apartments and other suites (Trainor et al. 1993). Supportive housing provides better opportunities for participation in the larger communities than institutions (Ambtman 1990), and it may also increase consumer's participation in the community more than independent living, since supports would minimise the tendency of people to isolate themselves if this was an issue.

Most recently, a community integration model of housing has been conceptualised and developed, where consumer/survivors are active and valued members of the geographic community where they reside (Carling 1995). Housing that promotes an integration framework would provide opportunities for people with disabilities to access generic community resources and interact with other members in the community enabling the development of meaningful relationships and roles (Aubry & Myner 1996). In current studies greater social integration and belonging to the geographical community was linked to an increased quality of life for people with psychiatric disabilities (Aubry & Myner 1996). Community integration is the most current model with respect to housing individuals with psychiatric disabilities in the community. Consumers have moved away from their historical pathological labels and are currently demanding that they be seen as equal participants in the affairs of the community, and are also demanding affordable and suitable housing with supports, as defined by themselves.

However, researchers also discovered that people who reside in supportive housing continue to be excluded from making meaningful relationships and having valued roles in their geographic communities (Aubrey & Myner 1996). People with psychiatric disabilities who

reside in supportive housing continued to be isolated and lonely (Livingstone & Srebnick 1991; Hatfield 1993). One rationale for isolation is that people with mental illness living in supportive housing experience decreased social supports when compared to other individuals in the community. Boydell and Evertt (1992) suggest that this is due to societal factors and not the supportive housing itself. They indicate that stigma has an effect on reducing social contact with others in the community due to negative perceptions of people with psychiatric disabilities. Estroff (1981) emphasised that consumers continue to be ostracised in the general community, and usually have other consumers as their only informal supports.

STRUGGLE FOR IDENTITY

The psychological well being of consumers/survivors who live in the community was also reviewed as it relates to active community involvement. Despite many positive changes with respect to reducing the oppression toward people with psychiatric disabilities, their acceptance by other members of the geographic community is tenuous. During the past few years, legal charters protecting the rights of all citizens have been paramount in challenging institutional and overt oppression, thus blatant discrimination is less prevalent today. In a 1990 review of Canadian research focusing on people with psychiatric disabilities, Page & Day (1990) illustrated that the community verbally stated that they would accept people with psychiatric disabilities and overt discrimination was reduced, yet exclusion in employment and housing was common, and the media continued to display oppressive images of people with mental illness. A study by Aubry et al. (1995) found that at least seventy percent of community members indicated that they would engage in superficial contact with a neighbour yet they were unsure and guarded when told that the neighbour may experience a psychiatric disability. The results of this study were similar to the findings of Link & Cullen (1983). The opportunities for consumers to participate in the functioning of community is markedly diminished through exclusion and stigma. Furthermore,

any citizen who has difficulty identifying with the community will experience apathy and lose the chance of acquiring a useful role for themselves (Cox 1987).

Modern oppression and stigma toward consumers is deeply rooted in the institutions of society and within some of the agencies that have historically treated and supported people with psychiatric disabilities. People with significant psychiatric illness have many barriers to accessing community resources and services. In some cases social service agencies instituted practices which indicated that people with mental illness were not wanted (Johnson & Rubin 1983). For many consumers/survivors in the community, oppression is as insidious as not having a voice or control with respect to mental health services (Lord & Dufort 1996). Many professionals have verbalised support for consumer empowerment in the planning and delivery of health service but this practice is difficult since most of the institutional oppression and power is not a focus for discourse, and a hierarchy with professionals at the top is not viewed through a critical lens. Many practices of mental health services continue to construct barriers to full consumer participation. It is difficult for consumers to obtain paid work positions in the field of mental health due to academic and work history criteria, and many institutions and programs develop policies and procedures without the input of people with psychiatric disabilities (Carling 1995). There are an insufficient number of studies that have analysed the privilege and power of mental health professionals (Lord & Dufort 1996). Many individuals in the community also perceive the power of knowledge to be so legitimate that professional expertise is given priority over the experience of the consumer/survivor or their family member (Lord & Dufort). Considering the oppression that consumers face by the community and the systems developed to provide service to them, it seems justifiable to state that stigma is a prevalent factor in creating barriers for individuals to access valuable roles and develop an identity.

WORKING WITH CONSUMERS AS PEOPLE AND NOT PATHOLOGY

A fundamental paradigm shift is occurring in North America with respect to the treatment

of people with psychiatric disabilities. In the last century treatment of people with a mental illness has evolved through three distinct phases (Carling 1995). Historically, people with psychiatric disabilities were institutionalised in large hospitals where they had little or no self determination in treatment or support. Then deinstitutionalization occurred to fuel the development and rehabilitation of people with mental illness. Within deinstitutionalization, consumers continued to be seen as deficient and in need of rehabilitation to adhere to societal expectations and structures. Lastly, a move beyond *treatment* has taken place in some facets of mental health. Consumers and their families are demanding a holistic view of mental health that includes self defined support and resources, all moving a person towards inclusion into the community of choice. In order to move to inclusion, one is required to focus on the strengths, talents, capacities and resources of the person who experiences a psychiatric disability rather than the pathology (Weick et al. 1989; Tanzman 1993).

Professionals have to move from a model of practice where individuals are the focus to one where community change is the primary objective if we hope to advocate for, and empower individuals (Wilson 1996). Runyan and Faria (1992) state: "However, if true "community" care and integration is to be achieved, the community cannot be ignored. It must be counted on as an ally and it must become a major target of intervention (pg. 51)". Runyan and Faria (1992) suggest that community involvement and education is required to reduce the segregation and isolation of individuals with psychiatric disabilities.

Direct practice with individuals also has to be viewed critically. According to the 1993 Strategic Mental Health Plan for B.C., choice and control over supports and services are paramount to holistic care. The plan also emphasises the importance of accountability to those receiving service in the community as is prevalent in other health care sectors. It is necessary

that consumers define their needs for the mental health system and determine how they are to be met (Wilson 1996). In some instances, peers may be the most suitable candidates to support and promote wellness for consumers. The experience of coping with a psychiatric crisis and understanding the pain involved may motivate a consumer to help others with similar experiences (Francell Jr. 1996) which validates the increase in self help groups and agencies.

If professionals chose to promote well-being for consumers, they must focus on the person's entire environment and avoid the identification of people as psychiatric deviations. Positive mental health is determined by the interactions between the person with a psychiatric disability, their geographic community and the environment where (s)he lives (Wilson 1996). Wellness is also contingent on acquiring basic material resources such as income, housing, transportation, and subsidies (Tanzman 1993). It is reasonable to expect that the stresses associated with financial struggles would be substantial for individuals that may also be dealing with a psychiatric disability simultaneously. It is essential that each person in the community have the means to satisfy their basic needs such as housing, food, and social support. People with psychiatric disabilities could gain power through avoiding victim blaming rhetoric and re-centering their actions and analysis on the environment where they live (Lord & Dufort 1996).

MEANINGFUL ACTIVITY

Contemporary researchers using an integration model are now involving consumers in planning at the community level and this is leading to many benefits. Consumer's experiences are vital with respect to participation in planning mental health services. The lived experience of coping with a psychiatric disability is important and legitimate knowledge (Mason & Boutilier 1996; Carling 1995). Researchers and mental health professionals must respond to the need for

empowerment by balancing the relationship between professional and *client*. Professionals have some knowledge and skills, but consumers/survivors can teach the worker about their lives, culture and environment (Hardcastle et al. 1997). When consumers are acknowledged for their experiences and abilities their lives were found to be improved (Mason & Boutilier 1996; Park et al. 1993). In order to utilise the skills and abilities of people with psychiatric disabilities they should participate in the planning and research as co-researchers and participants. Through full participation in all research activity, the consumers can be increasingly focused on structural change as an end (Mason & Boutilier 1996). Consumers will be validated for their legitimate knowledge and skills through participatory research, which would also have effects on an individual level by creating opportunities for community participation and belonging. As researchers and participants in research, people with disabilities would develop relationships, be connected to social activities in the community, develop personal skills such as social skills and vocational skills, have access to material resources, and also develop awareness of community resources (Carling 1995).

Consumers may also be empowered through a participatory approach in the planning of health care and supporting other consumers; thus one can be empowered through the sense of belonging and contributing in the community where they reside (Rissel 1994; Lord & Hutchison 1993). People who participate in health care planning and resource allocation gain access to valuable social roles and social support networks in the community (Wilson 1996; Lord & Hutchison 1993). Involvement for consumers can also be valuable in terms of personal and vocational growth. On an individual level, one can gain self esteem and confidence (Wilson 1996; Lord & Hutchison 1993) From a developmental standpoint, the involvement can increase organisational and vocational skills as well as enable participants to be mentors for other

consumers in their community (Wilson 1996).

FRIENDS AND SUPPORT: PLACES OF BELONGING

Little research has been completed that explores the well being of consumers/ survivors with respect to the support they offer others in the community including people who do not experience a psychiatric disability. Research is required to facilitate discussion about roles for consumers in the community, and one needs to see a consumer as an individual with merit that makes them comparable to any other citizen in the community (Hardcastle, Wenocur&Powers 1997). Aubrey et al. (1995) discussed the notion of neighbouring and its' relationship to healthy communities. They conceptualised neighbouring as social contact of a supportive nature between individuals living in geographical proximity. Reciprocal supporting and belonging are common themes when discussing the notion of healthy communities. However, there is no available research on how people with psychiatric disabilities define their community illustrating tangible things that are needed for well being. Reidy (1992) found that consumers require access to valued roles in society, and need to participate in life-enriching activities in the community to be an active participant.

When we speak of community with respect to people who experience a psychiatric disability one often refers to the geographical location in which that a person resides. The geographic community may be the community with which the consumer identifies; but his/her community may not be limited to their area of residence. They may define community as a group of people with shared interests, shared language, shared culture, or where an individual feels that they belong (Christie 1997). The individual consumer is inevitably linked to other structures in the geographic community, and this network of ties could be used to define community. As a

member in the geographic community a person with a psychiatric disability could be networked to family, church, volunteer work, and so on (Martin & O'Conner 1989). In sociological history, individuals gain their sense of self, at least partly, from their relationships with others in the community. And through these relationships, one can obtain a sense of belonging and security (Weil 1995). Communities are functional for individuals who reside within their boundaries. Communities provide opportunities for socialisation and the subsequent transfer of knowledge, opportunities for social participation, and occasions for citizens to engage in activities of mutual support (Warren 1972). Friendships are developed through regular community participation and actual belonging through jobs, school, and leisure (Carling 1995).

Considering the differences in defining community within the literature, one would have to utilise consumer input to gain information on how they define community for themselves. The experience of sharing a psychiatric disability among members of any group could also represent community (Christie 1997). The individuals with the most knowledge about the consumer community, and characteristics associated with such, are the people who experience a psychiatric disability and those who are close to them. In maintaining mental well being in the community consumers play a vital role in supporting and assisting other consumers (Christie 1997; Carling 1995). It is vital that experts in the mental health field work in partnership with consumers, their families, and the remainder of the community, since all play a role in promoting wellness for individuals.

Education is important in order to include the wider community in promoting well being. The best educators with respect mental health are those who experience the primary effects of psychiatric disabilities such as consumers and their family members in conjunction with professionals (Runyan & Faria 1992). To understand a consumer's community one has to become connected to the people in the community in some way. To gain an understanding about supports as they relate to consumers, it is important to obtain in-depth knowledge of individual

consumer's lives, and gain information on their social connections without attaching psychiatric jargon (Reidy 1992).

THE RESEARCHER RELATING TO THE DATA: FOCUSING ON STRUCTURAL POWER AND CHANGE

For this study, I chose to focus on the individual consumer/survivor as a participant in the geographical community. Within the context of community or any group where oppression and marginalisation occurs, it is apparent that power and the structures that promote inequities require critical analysis. The mental health system is one of the many institutions that historically has had power over people with psychiatric disabilities. This is supported by Lord & Dufort (1996), "Understanding oppression within social context and social structures, as well as the personal, is essential for a full analysis of power and oppression in mental health. It is also the basis for supporting resistance and empowerment" (pg. 7). Within the framework of structuralist theory, one can strive to understand oppression, its dynamics, and the social functions it carries out through structures in society (Mullaly 1993). When marginalised individuals begin to understand the power in the institutions around them, they will be motivated to join in the protest and force changes (Cox 1987).

To understand structuralism, an individual has to be aware of their personal definition of oppression since many people define it differently. In order to define oppression one must simultaneously define what it is not. Oppression cannot be deduced to be those actions which stifle self determination and are rights limiting because in that case all individuals in society would be oppressed through some means. Oppression transpires when limits occur for an individual not because of their talent, merit or failure, but affects them because they belong to a particular group (Mullaly 1993). Oppressive institutions and agencies protect a certain kind of citizenship generally consisting of those with patriarchal and neo-conservatist values (Mullaly 1993).

According to Mullaly (1993), when the analysis of oppressive functioning is narrowed it

can be reduced to two integral components. Firstly, those with power can marginalise others through social control. Consumers/survivors have experiences such as involuntary hospitalisation and forced treatment that certainly falls within the realm of social control. Secondly, those in positions of influence and power create a type of *"ideological hegemony"* (pg. 158) where they create control through manipulating institutions and ideas. This control over another group of individuals can be exercised through education, religion and the mass media. Its purpose is to distort knowledge and ideas to create beliefs about any group that threatens the status quo. People within marginalized groups are also subject to the ideas passed on by people with power so they will internalise oppression into cycles of self blame (Mullaly 1993). People with psychiatric disabilities are often presented in sensationalistic stories through the media, and are associated with many other social problems, such as violence, without sound supportive evidence.

Fundamental to structuralist theory is the notion that each individual ought to view their work as an integral element towards social transformation (Mullaly 1993). Mental health practitioners find themselves as perpetrators of the oppression that they are obligated to struggle against. On the employee level, workers are affected by societal priorities and public order, rather than the well-being of the population they are serving (Mullaly 1993). Social workers can practice within a conventional framework where they acknowledge social problems but define them in the context of personal difficulties and choose to assist marginalised people in coping or adjusting (Mullaly 1993). Skill teaching and personal treatment plans have been a mainstay in the field of mental health services for many years and this infrequently occurs in conjunction with the critical analysis of institutional oppression or power. Social workers are often unaware enablers through paternalistic practice who believe that the control of the oppressed is positive for the society as a whole (Mullaly 1993). Social workers in British Columbia have the influence to force people into treatment against their wishes in the best *interest* of the community under the direction of the Mental Health Act. They are members of multidisciplinary teams working with individuals as primary workers in institutions such as hospitals and mental health centres where

individuals are provided with services against their will.

However, workers in community agencies can also incorporate an alternative or critical view. When workers use a critical perspective, they will not believe that current institutions are capable of adequately meeting human needs (Mullaly 1993). My observations and personal experience in the field of mental health suggest that the current systems and institutions are unable and often unwilling to meet the needs of consumers/survivors. Current services are overwhelmed with the numbers of individuals seeking support, and there are hundreds of people with psychiatric disabilities who are currently residing in substandard housing, and many are homeless. If social workers are to adhere to the values of the British Columbia Association of Social Workers code of ethics they would be required to espouse principles such as the right for all to develop to their potential and to be free from exploitation. People who chose to practice social work ought to practice within a humanistic framework which is based on the universal nature of human need (Mullaly 1993).

When a worker makes the decision to practice within a structuralist perspective, he/she must focus on, and understand the power inherent in institutions and agencies and the means that are used to oppress marginalised individuals. Each worker ought to assist individuals in increasing their power over organisations and institutions (Hardcastle et al. 1997). We must perceive that empowerment is a holistic concept that encompasses one's personal, social, political, and economic life. A structural social worker would practice on three levels that consist of the worker, agency and social policy (Mullaly 1993). A worker should use critical analysis on the worker level (individual) focusing on his/her practice with the people that are the focus of the intervention. They should also understand the power inequities within their agency and work to support equality. All agencies are subject to the system that they operate within, and each worker should understand the structure which promotes philosophies and priorities which in turn promote power imbalances. Lastly, each individual worker must understand the role of social policy and its implications with respect to promoting the interests of the dominant groups, over those who are most vulnerable.

It seems that the focal point for structuralist practice is to increase the means by which marginalised groups communicate and share knowledge (Mullaly 1993). When people with psychiatric disabilities share information about their lives and experiences to other consumers they begin to look critically at the structures used to provide service which limit their participation in the communities where they reside. It is less difficult for an individual to pathologise his/her experience if many people who share a commonality (having a disability) have similar experiences. They then are more likely to move to a critical perspective of the institutions and structures that are involved in their day to day affairs. A focus group would promote and nurture this process.

CHAPTER 3
METHODOLOGY

SUPPORTING A QUALITATIVE FRAMEWORK

The communities where the research for this project occurred are located in the suburbs of the lower mainland in British Columbia. Since a small sample was used in the research the need to maintain confidentiality for some of the participants was essential for their consent to participation. The geographical communities where the consumers reside are diverse in terms of culture and socioeconomic status. The participants were all from low socioeconomic backgrounds, with all collecting financial assistance of some form. Five women and three men from different cultural backgrounds agreed to participate in three separate focus groups situated in three different communities. Even though the participants had differing cultural backgrounds they were predominantly of Western European descent.

A qualitative design was chosen as the best method to provide information for the research since the study is exploratory in nature and it is essential for the research to focus on experiences of individuals with psychiatric disabilities. Consumers have extensive knowledge about their own experiences and are able to describe the keys to their well being as well as any other citizen in the community. (Carling 1993) recommended that further research is needed from the standpoint of people with psychiatric disabilities. A qualitative method allows the knowledge produced to be grounded in the experiences of the participants. The information produced in this study is built from the experiences of the participants, who are people with psychiatric disabilities that reside in supported housing.

Since the study is exploratory in nature, the research is not grounded in the researcher's assumptions or hypothesis. Without a hypothesis as a guide, the data was utilised as the framework for producing information. All of the findings in this study were formulated from the data, and the data was not used to support a previously held view with respect to how consumers/survivors perceive community.

Most importantly, I could not justify the process and energy involved in research without identifying myself as an active participant. Qualitative research allows for, and supports the notion of subjective research. Fundamentally, all research, both quantitative and qualitative have subjective aspects since researchers are not value free entities. Researchers within a qualitative framework interrelate with the participants, thus they engage in the production of knowledge together. All people have knowledge and theory built from life experiences. Qualitative work allows a researcher to be subjective in their work, and be an active participant in the data production. In this study, I participated in the focus groups as a facilitator, and provided participants with information about myself with respect to my theoretical frameworks and spoke of my personal experience in the field of mental health. During the process of communication within the groups, I provided prompts to some participants and promoted participation from all. On occasion information was added in an attempt to be supportive and to gain trust. All of the participants allowed an outsider to develop a method where reciprocal information sharing occurred. Individuals who participate in research ought to be acknowledged for their merits and one cannot understand information from their standpoint without participating in the process of data production. The focus groups allowed for data production in the context of group dynamics and process, where the facilitator inevitably plays a role.

FROM THE STANDPOINT OF CONSUMERS/SURVIVORS

People with psychiatric disabilities are somewhat different from other citizens who reside in our communities. They are different, just as women are different from men, and people of colour are different from white Westerners. The distinction of being different from those in positions of power in our community will result in a markedly different experience in daily living. Standpoint theory is based on the lived experiences of those individuals who live in the margins of society. Citizens who live in the margins have little power, and reduced means to access power to create beneficial changes. One's standpoint emerges from her/his social position

with regard to gender, culture, colour, class, and disability (Swigonski 1993). Regardless of the barriers created by an individual's disability on a personal level, they are subject to domination due to being grouped as different and threatening to those protecting the status quo in our society and communities. Less powerful members of society will experience a different reality than those in social positions of power as a consequence of their oppression (Harding 1991).

People who live in the margins of society suffer injustice and inequality in their lives. The inequality is not only prevalent in the realm of material resources such as housing and finances, but is also apparent in the lack of production of legitimate knowledge within the context of the community and academia (Kirby & McKenna 1989). Research within many disciplines has been dominated by the Western European male for a substantial period of time. In the past, barriers have been constructed to prevent individuals with different perspectives from participating in research and promoting their realities with respect to changing oppression in society. People with disabilities, women, and people of colour are just a few groups who have been excluded. Historically, relatively few people in non-dominating social positions have been able to create knowledge through their research, and present this as the objective truth (Kirby & McKenna 1989). Very few researchers experience a psychiatric disability which has resulted in treatments that are defined by *others,* who have the power to influence many spheres of an individual's life.

To utilise standpoint theory researchers must identify the research questions grounded in the reality of the marginalized group that is the focus of the study (Swigonski 1993; Harding 1991). Research from the standpoint of people with psychiatric disabilities will look markedly different than most of the current research in the field of mental health. Such a researcher will have to look beyond the biases of the previous work in the field that were mostly grounded in the medical model, focusing on individual treatment and rehabilitation. As a researcher, I will be required to move to a methodology where the marginalised group will not only participate and produce knowledge; their reality will be moved from the margins of research to the centre (Swigonski 1993; Kirby & McKenna 1989). In order to value research participants, one has to

use their wisdom and experiences in a manner that promotes their empowerment and well-being. When a researcher designs a project, standpoint theory requires that the research be completed to advance the cause of a disenfranchised group (Cook & Fonow 1990).

Within the framework of standpoint theory a researcher has some primary and secondary goals vis a' vis their project. The primary function of the research is to provide opportunities for individuals from an oppressed group to participate and promote their realities. Secondly, the participants will have opportunities to gain an increased critical consciousness. Participants in standpoint research may gain an increased awareness of their location in the social structure and the relationship that this has to their lived experiences (Swigonski 1993). Consumers/survivors may identify those common experiences that are related to their position in the social structure that had previously been identified as relating to personal inadequacies. It is possible to perceive that participants may relate to their lack of belonging and participation to their social location rather than lack of communication skills. A researcher within a standpoint framework would also have the advantage of working with participants who have an increased awareness with respect to personal participation in the community. In order to survive, people who are marginalised must have a type of double vision or consciousness where they have awareness of the dominant group's view of social structure as well as their own (Swigonski 1993). Consumers have insight into the beliefs and values of the dominant group, thus can behave in a way to ensure that they are accepted. However, they can continue to maintain their own values as members of the consumer community connected with others who experience a psychiatric disability.

A researcher who is interested in pursuing standpoint theory must examine her/his personal social power, and how it may appear in the research project (Swigonski 1993). As a white male and a mental health professional, I am aware that I am in a position of power with respect to people who experience psychiatric disabilities. As a person in a position of power, I feel that standpoint theory has important value within this methodology. It can facilitate a partnership with consumers in the building of knowledge through research and enable some

power sharing. However, I should not underestimate the difficulty in developing relationships with participants due to professional position and relationship to the power structure. I will share my biases that support consumer self determination and critique power within this paper in the discussion section. I also shared this information with people in the information sessions prior to asking individuals to participate. From a standpoint perspective there is no possibility of a value neutral perspective (Swigonski 1993;Harding 1991), and I can be aware of my biases, and document how they will affect the study.

One of the main theoretical constructs for this study is standpoint theory. I intended on exploring the perceptions of community from the standpoint of people with psychiatric disabilities who reside in supportive housing. However, as the researcher, I interacted with the participants and with the data, thus my perspectives and beliefs are intertwined in the process. This process of relating to the data is emphasised by Coffey & Atkinson (1996):

> Our knowledge is the outcome, we believe, of transactions with the social world, shaped by our methods of inquiry, and of transactions with the data we produce, shaped in turn by our ideas and analytic procedure. (pg. 15)

In order to follow standpoint theory in my study it was important to ground the research in the realities of the participants. The information generated through the qualitative method is grounded in the process and experiences of the group with connections to my experiences and involvement. I attempted to ground the information and issues in the social realities of the participants based on their definitions of the social world rather than a reality defined by policy makers or other theorists (Coffey and Atkinson 1996 :pg. 5).

I interacted with the participants and with the data produced from the focus groups. I utilised a Hermeneutical interpretation which was the interaction that I experienced as I related my experience and reality juxtaposed with the information that was provided by the participants. I began a *dialogue* between my experience and the information that was produced in the process

of the focus group. The process of making sense out of the data using my experience as a focal point is a major principle in Hermeneutic interpretation (Kvale 1996; Tesch 1990). During my role as facilitator in the first focus group, I began to look at concepts and ideas as they related to the whole group, as well as their relation to my own perspective (Kvale 1996). Within the context of Hermeneutical inquiry I wanted to gain a deeper understanding of the data by repeating the reflective process of looking at the data as it related to the world view of the participants and myself on a number of occasions. This repeated reflection and inquiry is defined as the *hermeneutical circle (Tesch 1990; Kvale 1996)*. Through this repetition of the inquiry, I was able to create some understanding and reduced the data to six major themes. The circular investigation allowed for a narrow focus with rich information rather than superficial understanding with a larger focus. (Kvale 1996) explains this phenomena as:

> In the hermeneutical tradition this circularity is not viewed as a "vicious circle" but rather as a circular fructuosis, or spiral, which implies the possibility of a continuously deepened understanding of meaning. (pg. 48)

Within a framework of Hermeneutical inquiry I was able to ground the data in the experiences of the participants and create the information in the findings chapter of this paper. The analysis was based on my reflection of the data, utilising my own perspective as it related to the standpoint of the participants and their social reality.

WHY FOCUS GROUPS?

There were a number of reasons that supported the use of focus groups to explore the meaning of community, and participation for people with psychiatric disabilities who reside in supported housing. Firstly, focus groups are a method that supports a qualitative framework for

research. Focus groups allowed for diverse communication amongst participants and extensive data production. The groups allowed for the interaction between myself and the consumers in a session. It was a format that enabled me to utilise the interpersonal dialogue among the participants, since this communication is paramount to gaining a greater understanding of their experiences.

Secondly, information in the literature about consumer's perception of community is scant, and a focus on individuals who reside in supportive housing has not been pursued by researchers in the past. Given the lack of studies from a historical perspective, the focus of my research has been exploratory in nature. Focus groups have been identified as beneficial with respect to exploratory studies that require information rich data gathering (Krueger 1988; Carey 1994). Group dynamics, and interactions among members in this study can increase the amount and depth of information gathered.

Thirdly, focus groups allow for the normalisation of the interview experience for participants (Carey 1994; Krueger 1988). During the focus groups for this study, there was opportunity for peer support and personal connections between participants. Historically, people with psychiatric disabilities have been *studied* by professionals as if they were abnormal entities. Any method based on searching for abnormal phenomena in individuals during an interview is intrusive and oppressive. In an attempt to normalise the method of the study, I was attempting to share power, build trust, and promote support amongst the participants to increase their level of comfort.

Fourthly, the group process allowed for social interactions between myself and the participants. Through the social interactions I was able to support the participants and encourage them to participate by asking each of them open ended questions. During the groups I also had

opportunities to probe for more information when participants either required encouragement, or displayed discrepancy between the content of discussion and non verbal messages (Krueger 1988; Carey 1995). For example, a participant explained the supportive nature of their relationship with a professional and the tone of his/her voice flattened during this conversational focus. As the facilitator, I was able to increase clarity on the issues, through probing and asking the participants to expand when needed. Members of the group also probed other members by sharing similar experiences or asking questions.

Fifthly, focus groups allowed for information gathering within a reduced time frame. I was able to include the perspectives of eight individuals within the context of three different groups. I would not have been able to utilise this number of participants if individual interviews were chosen as the research method. Through the use of groups, I was able to increase the number of consumers/survivors in my sample, and complete the research within a reasonable time frame with limited resources.

Lastly, focus groups are used to ground the information in the experiences of the participants. Most of the previous literature in the field of mental health has been based on the standpoint of the researcher and consumers/survivors were not included in the knowledge production. Focus groups allow the researcher to understand an issue from the perspective of a specific population (Asbury 1995). The groups in this study promoted communication among the participants which enhanced the subsequent development of knowledge by utilising the conversation as the data collection tool. The audiotaped group sessions were the focal point of this piece of research, thus the consumer's experiences communicated in the process of the group is the foundation of this study and subsequent discussion in chapters four and five.

SOME DEFICITS OF QUALITATIVE FOCUS GROUP RESEARCH

With all of the positives of focus groups that were outlined earlier, one cannot dismiss some of the shortcomings of this type of data gathering. Focus group data adds another dimension to analysis since the group process and context needs to be considered. The data from the groups must be considered as a group discussion and not individual interviews, thus making it more difficult to analyse. There are many subtle nuances in group communication, all of which cannot be captured by the researcher.

Secondly, this study relies on qualitative methods for data gathering and analysis, thus the information was constructed, at least in part, from the transcripts of the audiotaped group interview. The transcripts decontextualised the communication from the group experience into a format on paper. During the transfer of information, some loss of meaning inevitably occurred. The process of decontextualisation is illustrated by Sandelowski (1994):

> Once an interview is transcribed, the transcript itself typically takes on an individual reality, but one that is constructed from the interaction between talk and the human beings who listen to and make choices about what to preserve. (pg. 312)

During the transcription of the group interviews the whole group interview was not preserved, only words in the transcripts, and notes about non-verbal behaviour that were made after the focus groups were conducted.

To reduce the negative effects of transcription I attempted to preserve features of the interview that I believed were important such as some non-verbal behaviour. I took note of pauses in the discussion that were realised when the transcripts were read while I simultaneously

listened to the audiotape. I explained the transcribing system that I used clearly to the transcriber when the information from the cassettes were transferred. During the transcription changes to grammar were made, and sentence structure was corrected to ensure that the participants saw that their discussion was logical and valuable when they received their own transcripts for editing. However, the content of statements was altered, which could have increased the likelihood of misinterpretation of the participant's word.

Thirdly, participants in a focus group may alter their responses and adjust their behaviour in response to the interactions with other group members and the facilitator which is defined as *censoring and conformity* (Carey 1994;1995). It is difficult to watch for censoring and conformity while facilitating a focus group, but one should be aware of the phenomena. I attempted to support each participant in the groups, and to validate their personal contributions on a regular basis to build trust and increase their confidence. I indicated on many occasions during the information sessions and pre-group instruction that each participant had valuable information from their personal experiences that was vital to the study. I was also aware of any personal connections or friendships that the participants had with each other through personal participation in the focus group, and clarified the extent of the relationships when an opportunity arose.

I was particularly sensitive to a censoring behaviour defined as the *difference effect.* This phenomena in groups occurs when participants communicate information that they believe will not offend the facilitator (Bernard 1994 pg. 231). People who are oppressed may provide censored information to a person they perceive to be in a position of greater power and influence. Historically, people with psychiatric disabilities have been oppressed within the context of research thus one can infer that they would experience some pressure in regards to the difference

effect.

Since one of the main goals of this research project is to present information from the standpoint of the participants I attempted to reduce the difference effect within the groups. During the groups I attempted to use support and humour to build trust and rapport. The participant's responses were validated when they appeared unsure of themselves. I stressed on a number of occasions that there were "no right or wrong answers" to increase clarification with respect to eliciting uncensored responses.

VALIDITY, RELIABILITY, AND GENERALISABILITY

It is difficult to assess the validity and reliability of qualitative studies, and some people such as myself, believe that these are just measures of quantitative research imposed on qualitative work. However, it may be advantageous for researchers to address validity, reliability and generalisability to increase the credibility of their work.

Validity is defined by (Kreuger 1988) as, "…the degree to which the procedure really measures what it proposes to measure" (pg. 41). Another way to phrase this question with respect to this study, is whether the focus groups created the means for individuals to provide their perceptions of community or did the group process create their experiences. As Krueger (1988) explains, it is better to focus on the results with "healthy scepticism" (pg. 41). The results from any study are not unequivocally valid, and each reader will be required to judge the believability of a project based on their own perspective. I can illustrate with some certainty that the participant's experiences of community was grounded in the data from the focus groups, and was not created through the group process. The participants had different perspectives and different realities, which they did share with each other during the process.

As mentioned earlier, the feasibility of focus group inquiry has many positives with respect to exploring the perceptions of consumers/survivors who reside in supportive housing. Krueger (1988) explained that a focus group procedure will be valid if it is used carefully for a problem suitable for focus group inquiry (pg. 41).

The most basic type of validity is *face validity*. This type of validity is determined by whether the results look valid on first inspection of the data and results. During the focus group sessions, it seemed that the participants were speaking about their own personal perceptions of community, and influences such as censoring and conformity were addressed and limited. (Krueger 1988) stated, "Typically focus groups have high face validity, which is due in large part to the believability of comments from participants" (pg. 42).

Reliability is defined by the consistency of a measure across different groups. Would the focus group technique in this study yield similar results if used with another group of people with psychiatric disabilities who reside in supportive housing? The answer to the question is probably no, but the groups for the purpose of this study do not have to be reliable. It seems that the reliability of data gathering methods is directly linked to increasing the generalisability of results. If the results of a study are generalisable then they could be projected on to the entire group that the participants are connected to. I do not claim that the information gathered during this study is directly applicable, or covers the experiences of other consumers/survivors who reside in supportive housing. Perhaps, if the method was utilised with enough persons, and no more new information arose, then the method would be more generalisable (Carey 1995). Despite the struggle to measure the reliability and generalisation of findings, the significance of the results should not be diminished. The participant's experiences that were gathered in this study will relate, at least in part, to other consumers who reside in supportive housing. Within the context

of a qualitative study where focus groups were utilised, it is prudent for the researcher to make broad statements about the findings with respect to relating the findings to other individuals in similar circumstances (Carey 1994 pg. 233). More importantly, the study is intended to validate their reality and create more questions about the meaning of community for people with a psychiatric disability in order to move their issues from the margins of research to the centre.

THE PRE-GROUP PROCESS

In traditional research, the questions and hypotheses have been constructed by mental health professionals. In order to focus the research on the standpoint of consumers/survivors, the experiences and questions must be clarified, and defined by the participants if possible. This shift in research practice is consistent with recent calls for research on psychiatric disabilities to focus more on the commonalties between people with and without disabilities, and to begin defining "success" in terms of quality of life variables such as physical and material well being; relations with other people; social, community, and civic activities; personal development and fulfilment; and recreation.

Social work practice has a fundamental practice principle of empowerment and the research generated should also be founded on the same principle. Mullaly (1993) explains that "Each social worker must see her or his individual work as an integral element of the larger movement of social transformation". (pg. 155) If empowerment is a primary practice principle, then research must allow for oppressed people to gain control over their life and build awareness about oppressive structures in their social environment. A qualitative study was empowering as it provided support and facilitated learning through validating experience and providing opportunities for participation in research. This participation was process that moved their experiences from the margins in research to the centre. It was essential to create the chance for

participants to be heard. Participatory research situates people with legitimate knowledge as active contributors towards creating new understandings (Mason & Boutilier 1996).

I wanted to focus on the experiences of individuals who had received some services from the formal mental health structure but also was hopeful that the individuals would have some similarities that could be dialogued with respect to community living and individual well-being. I utilised a purposeful sample of individuals with a criteria of selecting only those people who resided in some form of supported housing and experienced a psychiatric disability.

With the permission of the agencies contracted to provide the supported housing service, an information group was held at a Mental Health funded clubhouse in each of the communities. One agency sent introduction letters to all of the consumers who resided in their financially subsidised supported housing units. Approximately thirty-five letters were sent inviting individuals to attend the information meeting, and nine individuals responded by attending the information session where I explained the project.

The other agency provided word of mouth invitations through their support workers to the individuals who were provided with subsidies. The individuals were invited to one of two separate information sessions at the clubhouse that was nearest to their residence. At each information session I shared the information about the project that I felt was essential. I explained that I was a student interested in consumers/survivor's experiences and also indicated that I was a mental health professional. I attempted to explain some of the standpoint and structural theory that precipitated this methodology, and disclosed some of my personal experiences in practice with respect to institutions and the treatment of people with psychiatric disabilities which I find to be unjust and inhumane. Individuals were given the option of signing up on a sign up sheet or they could telephone me at my residence. In the first information group four individuals signed the sheet and no one called me at home, thus the focus group, had four participants. In the second information session, five individuals participated and two people signed up for the focus group. During this information group two individuals who were in attendance were precluded from participation since I had previous professional contact with

them. During the contact I was in an elevated position of power. I had decided earlier in the research process to exclude individuals with whom I had a prior professional relationship since the power that professionals have in clients lives is substantial from my experience. With such a great power imbalance I perceived that voluntary consent would be jeopardised.

In the last information session two people attended, and both agreed to participate by signing the sign-up sheet. All of the participants had a psychiatric disability and resided in a form of supported housing, thus a homogenous sample was acquired where individuals had some shared experiences and distinct differences. All individuals by the nature of their living arrangements had something to offer with respect to my primary research question (How do individuals who reside in supported housing define, and participate in community?).

I presented myself firstly as a student, but also disclosed myself as a mental health professional, which may have created some barriers around trust and power imbalance since relatively few individuals decided to attend the information sessions. However the lack of interest could also be linked to the systematic marginalisation and oppression of consumers in regard to research. When individuals have been excluded from active participation in research for such duration, it would not be difficult to perceive that they would be willing to take an active role. The explanations for lack of response could be linked to many different rationales.

I explained that my status as a mental health professional and student would be used for advocacy, and my primary objective was to promote participation and shared learning. As a professional and student, I provided the means for participants to be heard, and their goals for change will be inserted into the text of a graduate thesis. I also provided dinner at a restaurant after the first focus group for the individuals who chose to come. A ten dollar honoraria was rendered to the participants in the subsequent focus groups since time was limited for the participants, as the groups were held during the early afternoon. This remuneration provided some compensation for sharing their wisdom and time, and also served gratitude since I was gaining from them vis á vis completing a portion of my graduate research. In participatory research, reciprocal sharing and honouring is an integral component of the research process.

The sample consisted of eight persons in total, using three separate focus groups. There were four participants in the first group, and the remaining groups had two participants each. The group sizes were satisfactory since they were large enough to encourage the participants to provide information, but small enough to facilitate and provide focus when necessary (Krueger 1988 : 46). For this particular project the use of focus group was employed over individual interviews because I felt that peer support was essential to provide safety for the participants. Most importantly, the value of sharing experiences and gaining from other individuals in research is fundamental to standpoint and structural research. I postulated that people would gain by hearing that they were not alone in their experiences and avoid patterns of self blame. I also believed that there would be opportunities for consumers to gain insight into structural oppression through listening to other's stories.

I intend to use this study to promote personal awareness and empowerment, but there are some ethical concerns that require attention. Firstly, all of the individuals who participated in the study were participants in a discussion group, thus it was impossible to maintain strict confidentiality since I could not guarantee that the participants did not talk to others about individuals in the focus group. Secondly, there was a possibility that talking about oppression and stigma could possibly facilitate the release of emotions from past traumatic experiences, although, this did not occur to my knowledge. From my experience as a facilitator and practitioner, the catharsis from sharing past frustrations and anger is usually beneficial. There was opportunity for the group to find solidarity in shared experiences and gain some control by brainstorming for possible solutions. Lastly, I obtained informed consent when I asked the participants to identify the purpose of the group explained at the information session prior to our discussion.

THE GROUP DEMOGRAPHICS

All of the individuals experienced a psychiatric disability since this is a prerequisite to get into a supported housing arrangement funded by the Ministry of Health. The participants

resided in three separate geographic communities, which are predominantly white middle class suburbs in the Fraser Valley. One of the communities had a lower socioeconomic mean than the other two, but the effect it had on the participants is difficult to determine since all of the participants received social assistance and experienced poverty. There were three focus groups held for the purpose of this research project. The first focus group consisted of three males and one female from a variety of age groups. Four of the individuals present, including myself, were from a Western European background and one person was First Nations. In each of the next two focus groups the participants were women, again from Western European backgrounds. Since there were only two participants in each of the focus groups it increased the chance for conformity and censoring. The age of the participants ranged from early twenties to the mid fifties. All of the participants were from a low socio-economic background where housing subsidies and social assistance were the main financial resource.

THE FOCUS GROUP PROCESS

A focus group format was used to facilitate discussion since some similarities amongst the participants existed, which created some bonding (Morse 1994, Asbury 1995). I also took the opportunity to explain ground rules prior to the commencement of each group. Firstly, maintaining confidentiality was covered with respect to my role and the participants. I indicated that I would protect all identifying information unless the participants chose to be mentioned in the write up. It was also stipulated that the participants themselves would have to protect the information that was produced during the focus group process. All the participants agreed that they would not divulge any of the other participant's personal information to anyone outside of the group.

Secondly, the participants agreed to respect the different perspectives of all of the participants. Each individual who chose to answer a specific question or add to a discussion would be respected through refraining from interruptions. I also explained from the onset that individuals may disagree about particular experiences, and a search for a group common truth

was not the purpose of the study. The differences and similarities were equally as important.

I attempted to establish my role as a facilitator to increase comfort and build trust with the participants. From the onset of each group I explained that I was a support for each participant, and asked each participant the questions directly to provide validation for their perspectives. Prior to the commencement of the group, during the signing of the consent forms I reiterated the rights of each participant and stated that I would support them if they refused to answer any particular questions or respond to probes. The consent forms were signed prior to the beginning of the group session in order to observe the mental status of the participants, and to ensure that individuals were providing informed consent.

During two of the three groups there were breaks at the one hour point of the group interview to allow participants to have an opportunity to have refreshments or a cigarette, since none of the rooms allowed smoking. The rooms were set up informally with the participants and myself situated in a circle. Tables were used on participant's request, since I distributed the questions prior to the group, and some individuals wrote notes for reference. The circle was beneficial for facilitation since I was situated in a position were I could observe all of the participants and make eye contact. This was advantageous with respect to observing non-verbal behaviour.

I chose to utilise a tape recorder as the data collection tool over videotaping to increase the likelihood of participation. Historically, people with psychiatric disabilities have been *analysed* by professionals in the community and videotaping the group process seemed to be highly intrusive. I perceived that the potential to create barriers for the participant's comfort and trust outweighed the loss of data such as non verbal behaviour that could have been captured through the videotaping procedure.

The questions in the focus group were open ended to allow participants to determine the focus and content of the discussion (Kreuger 1988). A semi-structured interview guide was used to facilitate discussion with some parameters that pertained mainly to the purpose of the study. I wanted to focus on people's perception of community, but at the same time have limited

structure that would enable participants to focus on areas that they felt were relevant. The questions that I used did begin as general in nature, and as the group spent time together, the questions began to get more specific to ensure that information on the perception of community was provided. As the facilitator, I took an active role in the group using empathy and humour when needed but directing individuals back to the topic when necessary (Asbury 1995, Bernard 1994). Through prompting, I attempted to illicit more conversation from individuals when they became stagnated through prompting. The focus groups provided opportunities for peer support and did facilitate discussion because similar life experiences could be easily related to one another. Some individuals with psychiatric disabilities also have some difficulty in answering abstract questions, so I attempted to repeat some questions, and provided chances for individuals to be specific when necessary. Unstructured questions did create some frustrations for participants, but the participants did ask for clarification when needed. The questions in the guide were as follows: How would you describe your community? What would you do on an average day in your life? What people are important in your life? Why? What things do you like most in your community? If you had the power, what things would you change? The interview guide that had five questions for the group was a suitable number (Krueger 1988 pg 59) to obtain enough information with some specificity.

The focus group format produced in-depth discussion because the participants were generally comfortable with each other and were supported. A safe environment was promoted where everyone had the opportunity to speak on every question. The focus groups were conducted in private rooms at each of the clubhouses, and this was accepted by the participants, since it was a familiar environment close to their homes. The focus groups were two hours or less in duration. I thanked all of the participants personally at the conclusion.

At the conclusion of the focus group interviews, the audio tapes were transcribed to preserve the data on paper. I completed the transcription of the first group's conversation. The sentence structure and grammar was corrected, but incomplete sentences and statements were left untouched for further clarification on behalf of the participants. A transcriber was contracted to

complete the next two transcriptions, following the same guidelines that were implemented during the first transcription. All Identifying information was eliminated from each transcript after it was completed.

After the interviews were transcribed, each individual was mailed a copy of their portion of the discussion with the pertinent questions, with the opportunity to make changes, deletions, and clarification. Each participant was provided with a stamped envelope to assess their transcripts and return them at their convenience. Only three of the transcripts have been returned to date. The corrections made in the returned documents were only grammatical in nature, and none of the individuals chose to change the content of their responses or delete any information.

ANALYSIS

Prior to the commencement of the analysis, as the researcher, I needed to clarify my active role in the development of this piece of research. I had to acknowledge that I was going to have a role in the shaping of the information presented in this paper with respect to adherence to my beliefs and values. I am a white male, and also am a practising mental health professional. Through these designations, I am a member of the group that has historically been most oppressive to individuals who have experienced psychiatric disabilities. As an individual with privilege in the mental health system, I have also experienced and gained a greater understanding of the structures and institutions that have been constructed. Through my experience it is evident that institutions such as hospitals and community mental health centres have constructed policy and practice with little input from people who are utilising their service. Legislation, such as the *Mental Health Act* also was developed with little regard and involvement from people that are most profoundly affected. In my experience as a student, professional, and community member I have found structural oppression that affects the lives of consumers/survivors. Some of the experiences that I have had were validated by (Kirby & McKenna 1989);

1. Knowledge is socially constructed
2. Social interactions form the basis of social knowledge

<u>3.</u> Different people experience the world differently

<u>4.</u> Because they have different experience people have different knowledge

<u>5.</u> knowledge changes over time

<u>6.</u> Differences in power have resulted in the commodification of knowledge and a monopoly on knowledge production

People with psychiatric disabilities continue to be seen as *different*, from the perspective of others in the community. Individuals who are different from the people who have power in society, experience the world from their particular perspective. I believe that an individual's perspective is influenced by his/her gender, colour, socio-economic status, and disability.

The preliminary analysis for this study began when individuals situated themselves in the room for the focus group. Some of the individuals asked permission to sit in certain seats, and others appeared comfortable and sat without any direction. It appeared as though none of the participants were aversive to being situated close to myself, since all three of the interviews occurred with the group members sitting close to myself and the tape recorder. I made an effort to make mental notes in regards to the participant's eagerness to participate and respond to questions. Some of the individuals who participated required direct questions; as others communicated spontaneously once a question was directed towards the group. As individuals responded to questions, some would speak until most of their ideas were exhausted, while others required some prompting to continue, or clarify themselves.

During each session I also attempted to focus on the volume and tone of the participant's responses. On occasion, an individual would change their volume or tone with respect to the content provided in responses. Their non-verbal behaviour was also noted during the group process. I situated myself in a position to observe all of the participants simultaneously, although the data with respect to non verbal behaviour and communication style was limited to my personal memory and some memos that I recorded following each group session. One of the key elements in this process was to search for discrepancies in an individual's participation (Carey 1994). If discrepancies arose during in an individual's participation in the context of the group, it

would require further analysis.

During my role as the facilitator I began my search for understanding within a hermeneutical framework. As I watched the individuals interact with myself and others in the group context, I attempted to link their responses and experiences to my own, moving between the two in a circular fashion. This circular analysis continued until the findings were reported in this paper.

Focus groups were used as the method of data collection thus it was important to look at the group context. It would be impossible to analyse the information from individual participants without situating the information in the group context. Group level analysis includes an interactional and sequential component (Carey 1994) which is difficult since a researcher is required to centre his/her attention on how the individual participants interacted with each other and the facilitator, as well as the sequence in which they interacted. I attempted to write memos recording some of the non verbal interactions after each group. Each individual that participated in this study had a relationship to others in the group where they shared information, and the group had an effect on them. It was important to recognise the group's effect on how individuals stated information, and when they chose the speak about certain issues.

After the audio tapes were transcribed I used a constant comparative approach to analysis. I read the transcripts while simultaneously listened to the audio taped interviews. I followed five guidelines that were outlined by (Krueger 1988 pg.115) as I proceeded through this process. Firstly, I attempted to consider the words that were used, and not just their overt meaning. Some examples of words that I analysed were contained in statements like; I'm *too sick*, I would be *shamed and ridiculed, unproductive, grinding poverty, feeling worthy.* All of these words have individual meaning but I asked myself questions about their emotional importance to the individual stating them.

Secondly, I examined the context of the statements made by participants. Did individuals comment, or elaborate on information that was put forth by another group participant? How much influence did I, as the facilitator, have with respect to creating areas of discussion? As the

facilitator, what was the extent of the influence that I had on the group discussion and focus?

Thirdly, I made an effort to concentrate on the internal consistency of the group interview. Did the participants alter their statements based on their interactions with myself as the facilitator, or through interaction with other participants. The interviews required a review of internal consistency to monitor for censoring, but was also important with respect to the sequential analysis of the data. For example, alliances among the participants could be determined by concentrating on the consistency of supportive statements towards a participant by other group members.

Fourthly, the specificity of information provided by participants on audio tapes and transcripts was analysed. Kreuger (1988) states, "Responses that are specific and based on experiences should be given more weight than responses that are vague and impersonal (pg.116)". Prompting was used on occasion and participants were guided to be specific if they were having difficulty articulating ideas. When ideas and portions of data continued to remain vague, the possible rationale for the indeterminate responses was explored. It is possible that individuals might have difficulty describing an experience if they do not understand it, or are experiencing negative emotional attachment to the event. Thus, erroneous or vague data may have substantial value if explored further through analysis.

Lastly, I attempted to search for some trends or ideas that were prevalent across the data and between the interviews by reviewing the transcripts again after centring my exploration on the intricate details of the comments. It was easier to focus on ideas that were similar across the transcripts when they were brushed over.

I moved line by line through the transcript to cut data items out and compared them to subsequent items to form categories (Glaser 1992, Kirby & McKenna 1989). During the process of comparing the data, I attempted to reduce the transcripts to a manageable size by dividing the information into portions which are referred to as "bibbits" by (Kirby & McKenna 1989). I grounded the data in the group experience and attempted to focus on the similarities and differences in the information. (Kirby & McKenna 1989) describe this process of analysis as;

This is done primarily through the constant comparison of data items with other data items until sections that "go together with" or "seem to help describe something" can be identified and located together in a category file. (pg. 130)

I moved through the material and cut out bibbits from the transcripts, placing the pieces that were similar together in different groups on the floor. The constant comparative analysis resulted in 39 different ideas (themes).

Once all of the transcripts were completely analysed, I attempted to compare the bibbits in the 39 categories to look for similarities and differences, "In essence, analysis consists of moving data from category to category (constant comparative), looking for what is common (properties) and what is uncommon (satellites) within categories and between categories" (Kirby & McKenna 1989 pg. 138). The information from the 39 categories was reduced and grouped into six major categories bases on their properties and satellites. The remaining six categories from the transcripts were placed in a labelled envelope according to the identified major idea. There were some satellite bibbits that remained that did not appear to fit any of the six categories and were subsequently placed in an envelope that was marked miscellaneous for further critical analysis.

Further in-depth analysis was then applied to the material in each envelope. The bibbits in the individual envelopes were then compared to each other, and related to my own personal experience, and my experience as the group facilitator. The interpretation of the data within each major category was grounded by the manner in which each individual bibbit, related to the whole.

CHAPTER 4

FINDINGS

The purpose of this study was to explore how consumers who reside in supported housing view the community. Most of the information in this section will be supported through the participant's statements and my perception of their responses.

During the analysis, six major themes arose from the interviews and they are as follows;

- Consumer/Mental health community
- Ideas pertaining to community change
- Positives of the community through support/subsidy
- Changes needed to support
- Barriers for community involvement
- Losses

None of the consumers will be identified by name or other demographic information, although those individuals who did not wish to be anonymous are outlined in the acknowledgements.

THE CONSUMER/MENTAL HEALTH COMMUNITY

When participants were asked to describe their community, most of the responses centred around a community of other people with psychiatric disabilities and the professionals in their lives. When the question was directed at each group, the responses lacked information about the neighbourhoods were they resided. However, the responses were information rich with respect to providing information about the consumer/mental health community. The lack of information about the geographic community is indicative of a reduced number of experiences in that context, and/or the reduced importance of that community.

The participants did speak about the merits of the community composed of other people with psychiatric disabilities, support workers, and professionals. One of the main institutions in the consumer community is the clubhouse. This is a contracted psychosocial rehabilitation

program that is funded through the province and community donations. The clubhouses that are referred to in this study are buildings, which are staffed by paid workers. When asked to describe their community, most of the participants included information on the clubhouse in their neighbourhood. The clubhouses provide opportunities for leisure and other activities.

> I like the clubhouses,…the clubhouses have different things that you can join like craft club and all kinds of things

> On other days when there are craft groups I'll spend most of the afternoon at craft class or just hanging out at the clubhouse talking and meeting new people.

It is also an environment where consumers can work with equipment and utilise some resources. There is technology available to people who do not have the means to obtain luxury items.

> Well, I'm too sick to work right, but I enjoy working on the computers so I can't afford one of my own and if I could, it would be so awful, it would be like a 286 or something, so I wouldn't even enjoy working on it so here---I can come here and work on nice machines and that helps me

> But I mean, I guess it does but it's just nice that I can go somewhere and have the use of equipment that ---It's just not feasible for me to purchase.

The participants also identified the clubhouse as an environment that allows for voluntary participation.

> People just come to the clubhouse, no one has to remind them, they just come because they enjoy coming. Independent choices.

It also offers the chance to be successful on some level and raise one's self esteem.

> Aww, get into all that sappy stuff about---how it helps my self esteem (slight laugh).

> But all in all it's mostly a safe place to be. The clubhouse is for the most part very positive for me. I have the opportunity to do things that I would not get to do outside, and I'd say like about my relationships with the people have been mostly positive and that's my community.

Some of the group participants indicated that the club program offered them most of their daily

contact and routine. The environment was nurturing and sustained their sense of well being.

> And there is a community within the community here. [the clubhouse]

> The [clubhouse] community you know, and that has opened up a whole new world for me. I couldn't function or nothing [previously].

> I've been able to come everyday and grow everyday. Before, I wasn't able to grow because of the community I lived in, and here it has opened the doors for me, for change and improvement, which there has been.

> …because she has just been really supportive of me and never makes me feel bad or anything. There are many members that I really appreciate around here.

> Little things like belonging to the clubhouse and being a full time member, stuff like that where people know you and your always coming regularly.

> And I have friends too---here at the clubhouse that I come and see which are important to me. I see them and I socialise with them.

During the group discussions, all of the participants indicated that professionals and

support workers were members of the community with which they were affiliated. Some of the

group members had difficulty relating their experiences to the concept of being members of the

geographic community. Most of the discussion created by the question [How would you describe

your community] revolved around the consumer/mental health community. Within this

community, it appeared that other people with psychiatric disabilities, professionals, and support

workers had a substantial role in building community for the focus group participants. Many

group members attempted to define their community as consisting of people who they have the

most contact with.

> Well in general, my community is that part of my life which includes other people which I have the most contact with in my daily life.

One individual identified three of four individuals as being members of the mental health community when asked who the most important people in his/her life were. Another participant replied "People that have a mental illness like I do" when asked [What people do you have most contact with?].

Some of the group members feel that they are more comfortable within the mental health community, although this may be due in part, to exclusion from their neighbourhood communities.

> As far as having no contacts {outside the mental health community} is fine with me, I really don't mind at all. I think I have a better life now than I did when I was on my own, before I was involved with mental health.

> And people who run the clubhouse and mental health. That's the only people that I can get along with actually.

> Where I do most of my living, and right now that includes being in the mental health system.

[When asked who were the important people in their lives] some participants could not conceive of any individuals other than professionals, support workers, or other consumers. It is interesting that there was a lack of responses about other individuals with who they have contact. One participant only identified his/her support worker, therapist, and the other participant in the focus group. Another participant responded quickly [when asked to define their community]

> Okay, well to start with, the mental health community, which includes the doctors, the therapists, the nurses.

and experienced difficulty with respect to commencing discussion about any other community.

Since there was diminished contact with individuals outside of the consumer/mental health community, some group members related how they had developed close relationships with

professionals or support workers and consider these individuals to be their friends and confidants. However, one individual disclosed that his closeness to staff at the clubhouse was important, but not quite *normal,* due to preconceptions about worker/client relationships.

> That's why staff are really important to me, and I think I'm closer than normal with a few members of the staff {staff of the clubhouse}.

The participants of the focus groups perceived that some of the barriers that separated worker from client had been removed. This change created opportunity for more close and caring relationships, which leads to greater connections.

> To begin with, I used to see a counsellor and she was probably at that time the most important person in my life, she was very helpful and caring almost like family.

> So those people, because of the way they are, not the role they have so much. But the way they express their role.

> The support workers are very important, they are very caring and helpful, always there for you, not just because they are doing their job, because they actually care about the clients.

> Yes, as strange as it may sound I always felt that they understood me more than my own family. Like they understand because they work with things like depression and they can understand more than your own family can.

The focus group members explained that the professionals and support workers continued to maintain their helping role. They are individuals in the participant's community who can be available for reasons of utility as well.

> Well right now I have two people in my life that are very important. My worker from mental health---and he's monitoring my condition because my condition seems to be changing all the time...And then next say my mental health worker cause they help me adjust---regulate my life better.

> I get to talk to them before I get depressed. They call and cheer you up a bit.

The group discussion in every focus group did consider the usefulness of professionals and other paid support workers that are involved in a supported housing model. All of the individuals who were present during the discussions illustrated how a professional or a support worker supported them in a manner that met their needs. Some of the support that was offered was individualised, to meet their needs

> [Describing important people] …then would be my community living support worker because she helped me with a lot of things like moving into town, getting subsidised, getting my handicap pension, and helped me move and stuff like taking me to apartments.

Skill teaching via a support worker was and important type of support mentioned by many of the individuals in the groups. Some of the individuals had lived in settings such as residential facilities and the family home prior to moving into a supported housing program, and did not acquire some skills necessary for success with respect toliving independently in a geographic community.

> She gets me to do my own cooking and cleaning and budget my money you know, just to help keep me on track with reality.

> Well I didn't go very far in school so I had to learn all over again, like banking. My worker before she was gone used to help me do it.

> If it weren't for this program I wouldn't be able to be on my own in an apartment and live on your own and also the workers they teach you a lot of things. {My workers} have taught me a lot of things like banking, things that I was afraid to do on my own before, and they are very good helping people with things like that for what you need later on.

> Unless they see that your not taking care of things then they will help you out and they will let you know but it they see you are doing all right then they probably won't mention anything.

Some people indicated that the support workers/professionals provided interpersonal support and validated their experiences. Many of the participants valued the time with the formal supports,

where they could be heard and their issues could be acknowledged as meaningful. This interpersonal contact is integral to feeling good about oneself according to some of the group members.

> [What do support worker do to make you feel that they are important] She know my illness and she says you have done well and she gives me confidence while some other people bring me down and say she is a nutcase.

> I do, I think my support workers have been excellent because I have arthritis in my legs and they listen to my problems and they really give me good advice and so does my therapist. They are a lot better than the city ones were in Vancouver.

The notion of hope was raised on a few occasions in the groups, and some people indicated that their support workers assisted in fostering hope. They perceived that they could share their plans about the future with their workers and be encouraged. One individual perceived that his/her relationship with a worker promoted the pursuit of personal goals.

> They are interested in what I have to say. They are interested in my opinions or my dreams, or my goals.

> As far as the SIL {supported housing} program goes, I've really enjoyed the support that I've gotten. Because, I'm considering going back to school in a years time and if it wasn't for the support that I got from my worker I don't think I would be as inclined to do it.

Participants also described the connections and contact that they had experienced with other individuals who have psychiatric disabilities. In all of the focus groups the individuals indicated that most of their contacts outside of the formal mental health system was with other consumers.

> Most of the people that I hang around with are from the mental health, and I prefer it to be that way.

The relationship with other consumers was discussed as reciprocal in nature, where support

provided and received was mutually beneficial.

> So I like to give as much as I can But I'm on the receiving end of that equation too. [So a mutual relationship?] Reciprocal, yes.

When the participants in the group had opportunities to share in social interactions they believed that they were integral components of a consumer community. They became a part of a social network in a community within the geographical community.

> When there isn't anything at the clubhouses that I am interested in I have a neighbour friend who is in the same program {supported living}. We go for a walk for a couple of hours and sometimes I'll go over to her place and we'll talk for a few hours.

When the participants related to the experience of belonging to the consumer/mental health community they began to depict the value of connections to, and closeness with others. For some of the participants, the consumer community offered friendships and intimate relationships were they could share experiences with other people. A few of the participants had not shared or were a part of close relationships for a number of years prior to their connection with the consumer/mental health community.

> You know it's people that make the difference. That's what is happening in my life---is people---where I had no people, no friends two years ago, nobody. My life has changed quite a bit. {Since being in the supported housing program}.

> I find now that I'm in this program that it is easier to make friends with other people who are in the program because they have similar problems and they understand a little bit more.

One of the consumers fondly mentioned a shared experience with another consumer attending the focus group discussion.

> We both like the same things. Our birthdays are on the same day. We had some coupons so we had pizza and they came with a strawberry shortcake with a candle on top, they all came and sang happy birthday to us.

Despite all of the benefits that the mental health community had to offer, some of the participants did share that mistrust of professionals and support workers continued to occur in their lives. Most participants stated that they had gained from belonging to the mental health community in some manner, and some people indicated that their mistrust was alleviated by the support and the relationship that was developed through support with professionals and support workers, who were also members of this community.

> {Internal feelings with respect to relationships with staff at the clubhouse} Having a life of their own, the cynical part and the trusting part at the same time because both experiences really do happen to me.

> Makes me mistrust them and become a little more cynical in some ways, and the new evolving support I get helps a little bit in the healing department, but both ingredients are there and arriving at the same time.

The consumers in this study tended to describe their community as the people that they had the most contact with. Most of the individuals tended to have contact with professionals and other consumers in settings such as the clubhouse.

BARRIERS TO COMMUNITY INVOLVEMENT

The participants in this study discussed many issues with respect to their lack of involvement in the geographic community. For the purpose of this project, the geographic community is defined as the neighbourhoods where individuals reside. Many of the consumers spoke about the benefits of their participation in the consumer/mental health community. However, all of them also disclosed that they did desire some involvement in the geographic community and had barriers to accomplishing this endeavour. My analysis of the barriers began

when only eight consumers decided to participate, out of approximately 70 individuals who
received some information about the study. My beliefs about the oppressive nature of research
were validated when only eight individuals decided to join the study. They may have decided to
abstain from participation due to power imbalances with me as the researcher, and/or because
research on people with disabilities has been oppressive historically.

The individuals that participated discussed some other barriers to their participation in
geographic communities. Some individuals disclosed that they perceived that they were
excluded from belonging to the geographic community.

> As far as the community goes, I feel if the community were more supportive and more
> open to people like us I would do more. If I received a phone call from anyplace in the
> community and they said we would like to get to know you better. We understand you
> have---you know your situation, and we would like to get to know you better.

> ...because I just see myself as not really belonging to the average society. I just feel like
> I'm outside of the average people.

Some of the consumers discussed how financial restraints created some difficulties with
respect to participation in the geographic community. They found it difficult to pay for
transportation to community activities even though some of them had acquired reduced rate bus
passes from the government.

> My community {named a municipality} is really quite busy, but getting around on the
> buses is really expensive. I have a bus pass, that helps out quite a bit.

> The problem with me is I don't have a bus pass so I just have bus tickets and sometimes I
> don't have enough to go to bowling way out in {named another municipality} so I usually
> just go to more local things where one bus ticket will get me both ways like the craft club
> and movie night and things like that {clubhouse activities}

> That's my biggest problem, like even going to the clubhouse you know, I like to go more
> often but the money only takes you so far.

For one of the individuals, the lack of financial resources prohibited him from being able to

participate in a leisure activity in the geographic community that would create benefit.

> Because I've done a lot of hunting in my past life and I like shooting guns and going
> fishing and stuff like that. But I haven't got stuff to fish, or money to join...

Some people had experienced difficulty when they applied for handicap pension which is

a status of financial assistance that recognises an increased financial burden for individuals with

disabilities. An approved application would entitle an individual to receive $771.00 dollars per

month instead of $500.00 - $590.00 under the auspices of financial assistance. Even though an

approved handicap status application would only slightly alleviate one's financial situation, some

of the participants discussed how they struggled with allowing themselves to apply because of

their feelings of guilt due to constructed perceptions on how they would burden society.

> Well I'm waiting but my feeling is that I shouldn't need it. Sometimes I feel that I'm not
> that ill where I would need it, then other times I feel that I could really use it. My doctor
> said to me once that people who apply for handicap are usually very ill, like
> schizophrenic who can't work for the rest of your life, but they look at me as able to work
> later on. I'm the type of person who doesn't like to take things that I don't need.

> Physically we are OK so that is why I feel very guilty getting all the things. I feel that I
> don't deserve it and that there are people out there that really do need it. Sometimes I
> think a lot about trying to get off of the program {supported housing} if it were up to me I
> probably would like to, but if I'm off the program it would financially be very difficult to
> be on your own.

Throughout the discussion it was evident that the individual's lack of participation in the

general community made it difficult to feel valued through not having valued roles. Many people

in the geographic community do not perceive that people with psychiatric disabilities have the

skills or knowledge to partake in a community role. Some individuals discussed how their

achievements and skills were minimised by others because they have a diagnosis of a mental

illness.

> Just one small incident when I was over at my brother's place. I was speaking to my oldest nephew an I said oh I've been to France and then he gave me kind of a putdown look, a sort of who cares kind of look.

> I don't know, I always think that people see me as lazy, that I am able to work but I am lazy and that's why I feel like everyone feels that of me. I don' know why. It just happens so quickly, I didn't even know about this program, my worker just got me into it because she thought I was having trouble finding a place to live on my own financially.

> And I told my dad that I was going to come speak at this meeting today. He said " you can't speak well at meetings". Now that was a putdown.

Some participants spoke about the barriers that their disabilities present. They discussed how their disabilities promoted isolation and created distorted self images that did not promote belonging to the general community.

> Well, because with my moods or the way I act sometimes. It's hard to explain, even in a job situation, I always feel like I'm not part of the workplace, I'm always separate…

> I don't go out because of the disorder that I have, it keeps me in a locked feeling. I spend most of my days just cleaning a lot and I have hobby where I collect fish so I take care of my fish.

One of the group members elaborated on how it would be difficult to access some the institutions in the geographic community. The education system was the institution that was discussed, and some barriers were brought to light. The intimidating nature of educational institutions was juxtaposed with how someone's disability may interfere with their success. One of the individuals had direct experience with difficulty in accessing, and being successful in educational institutions.

> …but I'm afraid of going to school, getting a student loan or something and ending up failing. Because that's what always what has happened, it's a pattern that has gone throughout my life for ages and I don't know how to resolve it…because I only have a grade nine education and because of lifelong problems because the illness has been there

for ages an it is the primary reason why I never wen t beyond grade nine.

Most of the participants spoke about the merits of the consumer/mental health community, and explained the benefits that this connection to a group offered them as individuals. However, this connection alone did not meet all of the individual's needs, and they wanted to belong to the geographic community as well. One consumer explained that he/she had belonged to the consumer/mental health community for a length of time and believed that she/he was was not able to relate to others in the general community.

> I don't really---I can't really, aw what's the word? Relate to people outside of the mental health community right now, which disturbs me, because I don't want to be like this... [What would you change] My friends, I wouldn't change my friends from the clubhouse here, but I mean I would relate more easily to people other than the mental health community.

A few of the participants discussed the segregation that they had experienced through being members of the consumer/mental health community. They discussed the perception that their continued contact with the consumer/mental health community represented that they did not have contact with others in the geographic community. The discussion centred on belonging exclusively to a community rather than concomitantly to both.

> That's just how I feel---not that there is anything wrong with mental {mental health community}. Lord knows I don't think there is but I don't like feeling so segregated.

> I'm so happy for this place {the clubhouse} and the people in it---I don't want anybody to get me wrong for that but I would really like some of my life to not have the word mental attached to it.

> As much as I feel comfortable with my own kind {consumers}, I also want input from people who aren't affected at all.

Despite the benefits of the consumer/mental health community, there was a perception that belonging to it precluded one's inclusion in the geographic community. It appeared as though

some individuals perceived the consumer community to be *lesser than* the geographic

community in value. They created a dichotomy between consumers, and other members of their

neighbourhoods. This was somewhat distorted since many people without a disability such as

myself, can be members of communities simultaneously. I am a member of a community within

a university, a work community, and also am a member of the geographic community where I

reside with my family.

POSITIVES OF THE SUPPORT, SUBSIDY, AND SERVICES

Some of the focus group participants had experienced their disability for a number of

years and they had witnessed some positive changes within the geographic communities where

they resided, and within the consumer/mental health community that they belonged to. The

attitudes of some of the professionals who were paid to support consumers changed and so did

the treatment. The interface between the consumer/mental health community and the geographic

community began to evolve. Individuals who had previously been housed indeterminately in

institutions began to live in neighbourhoods.

Many individuals resided independently but had significant struggles financially and

socially. The supported housing was developed to support individuals who had experienced

these difficulties. Some of the participants said that the supported housing program enabled

them to have more access to services in the community since they were able to afford buildings

in central neighbourhoods.

> Your services are available here where they won't be in other communities like when I
> was living in {another suburban community}. I had to take a bus down here and the bus
> only ran once every three hours and if I missed my bus then I missed my doctors
> appointment you know---for mental health.

Subsidy---well it's a good thing to have because before that I was living in a trailer, I was paying pretty cheap rent but I lived far from town so I had to have a car. And it took a lot of my money and soon as I got the subsidy I moved into {municipality}.

Well it's a large community and you're accessible to all kinds of amenities. The mental health centre is right downtown, shopping, clubhouse, stuff like that.

A couple of the participants indicated that their position in the supported housing program enabled them to have some participation in the geographic community. One person worked at his apartment complex taking the garbage out to the dumpster for some extra money. Another individual stated that she accessed a local eatery.

I go to the coffee hour at the {specific restaurant}, you get coffee for eighty six cents, that's really good. I know {name of server} and the people that are serving the coffee there.

Consumers who reside in some form of supported housing model are obligated to pay three hundred and twenty five dollars for rent. The remainder of the rent is subsidised by the province, and this subsidy does differ across the province of British Columbia since some communities have higher rental rates due to location and demand. Most of the participants in the focus groups indicated that their total rent was between $550.00 and $600.00 per month. The supported housing program provides financial support for all of the participants in the focus groups. For most of the consumers in the study, there was significant financial stress to reside in urban centres, where there are professional services available. The financial support had an effect on reducing the stress associated with living in poverty.

You know, where you have enough money to easily---not easily make it but to---no big problems and still have money left to be a real human being.

I like subsidised housing here, that's my favourite aspect, because before I was living in grinding poverty and I had my own trailer but I was living on less than five hundred

dollars a month you know, and it was pretty rough.

I would like to say that being on this program has been a good experience, something to look back on. It has been very helpful to help people out of financial trouble. It's probably the best thing that has ever happened.

The supported housing programs appeared to offer many of the group members some sense of security with respect to maintaining their shelter. The individuals have the rent paid directly to the owners, and the subsidy allows for securing shelter that meets their standards and needs. The consumers had security and were self reliant, which was different than their past, where some lived in marginal conditions.

That's really very important to me and I don't know about these others but I have a superior place now. I have a one bedroom suite---I lived with my parents till I was thirty four.

I think it all revolves around security and independence. When you have your own place secure, you have you own place that you don't have to worry about where your next rent payment is going to come from and your survival money.

I've been on welfare, I've been in the system for a long time, since I turned nineteen and the rents back then, they allotted you the same amount of money which is three hundred an twenty five dollars. Back then you could maybe find places for that amount, but now it is virtually impossible so anything beyond that comes out of your food etceteras.

Some of the group members explained that the money increased their opportunities in the community. In the past they had to struggle to meet their basic needs, and all of their energy went into surviving daily life. However, a subsidy took some of the financial burden from individuals and enabled them to consider their future rather than surviving in a level of subsistence. The minor financial gain provided some consumers with increased opportunities to participate within the geographical community.

It takes {off} a huge burden, where instead of worrying about money all the time you can actually worry about tangible things like getting an education, you know, and carrying on

with your life.

> I find that with subsidised housing I have more money and I'm able to do more things, participate in more things, it's opened doors for me just by having more money because of that.

Most of the participants discussed how they experienced loss of financial stability due to their psychiatric disability. All of the participants in this study were collecting social assistance for financial support, and none of the individuals were employed at the time of their participation. They explained that their hope about being accepted as workers in the general community was poor and they equated their disabilities with poverty.

> [on supported housing] I never had it so good. Well I did before I became ill but since I've been in the welfare system I never had it so good.

> ...I thought I was going to live in grinding poverty till I found a job that I could stick to for a while. Jobs out there are just so scarce, you know, you need a lot of education which I don't have.

Many of the group members agreed that the supported housing model has been helpful in facilitating independence and providing a stable place to live. The stability of the housing, subsidy, and support from staff and friends, had assisted some of the participants in avoiding some crisis.

> I mean if I got excluded from the program because of a time limit god knows where I'd end up, I'd probably go into hospital a lot more and I'd be going to places like {crisis facilities and transition homes} a lot more and my life would even be more screwed up.

> I agree with {names another participant}, I think it's a god send that we've been able to get on the SIL [supported housing program] program. Without it we wouldn't be able to live independently, semi-independently or which ever way your want to say it.

The previous information in this section explained the advantages and effects of the housing and financial support from the perspectives of consumers in the study. They also did illustrate the

merits of many human supports in their lives. The participants discussed a number of different levels of community involvement, with both formal (professional) and informal (family and friends) supports. Some of the participants described how they were members of their family community, and explained how they received support when they were experiencing difficulties.

> Well I say that my family in general has been more supportive over the years with my occasional hospitalisations or regression or whatever. But generally they have been pretty good.

> [On brother] He's very busy working so I don't see him very much but if I have a problem or if he has a problem then we always listen to each other and try to help each other out.

Some individuals illustrated the functional role that some family members had in their lives. Family is a support that can facilitate decision making and problem solving, and they can also promote activities of leisure and wellness.

> [A positive visit with brother] He comes in the summertime just for a couple of days then he goes back. He likes to go fishing. He drags me with a fishing pole, and out into the water.

> [On support from partner] Yes, we love each other very much. We've been through ups and downs and we know we will be together for long time and also in particular at when I'm considering going back to school. I have been considering it for the past few months. He has always listened to me and let me vent because I find that I'm sort of going through a roller coaster right now. Yes, I'll go to school or no, I won't go to school and I feel a lack of confidence on my part sometimes. He just listens patiently and them says "well dear, what ever you decide to do, I'll back you up.

DESIRED CHANGES TO SUPPORT

Many of the consumers who participated in this study did discuss concrete positives with respect to the support that they had received from professionals, support workers, and other individuals in their lives. Their connection to the consumer/mental health community was beneficial, because for some, it was the only community to which they belonged. However, they also discussed some changes that were required regarding the mental health community and supported housing. During the discussion, many distinct words were expressed about consumer's perceptions and negative experiences of support.

- *Controlled*
- My therapist is very *tough*
- My worker is *aggressively optimistic*
- *Forcing* those ideas
- Makes me feel *small*

The focus group participants discussed many potential areas that require some change from their perspective. The first issue of consideration was the actual housing since some members either had difficulty, acquiring accommodations in the geographic community, or their housing continued to be marginal despite having subsidies. The link between the mental health community and the neighbourhoods where consumers reside continues the need improvement. Suitable rental suites are scarce in many communities and subsidies do not create housing. It seems that many of the consumers who participated came from extremely problematic housing situations, or from homelessness in some conditions. Considering that some individuals came from no housing, or decrepit residential situations, they continued to make progress.

> I actually wish that our apartments were nicer. That's one thing that I wish but I had to take that one even though the linoleum in the bathroom was kind of yucky and at least the carpet was OK.

> ...it's not my dream home but it's certainly better than most of the places I've lived in. I

used to have a landlord that freebased all the time and I had another landlord that was always hitting on me and stuff like that.

It is also important to note that a couple of the consumers continued to care for pets and this also limited their housing options

> But I had to take that one because I have an animal, that's the only place that would take pets. {name of a subsidised housing development} doesn't even take pets and that's physically a really nice building.

One of the consumers explained that it was difficult, at times, to move his/her subsidy from one building to another. In addition, the buildings that have vacancies and are affordable attract other people in the community who are also impoverished, such as drug users. Even with a subsidy, some individuals indicated that it would be difficult to move to another suite somewhere in the geographical community where they wanted to reside due to the restrictions that some low cost housing developments have in place.

> Say you moved into a building where you got four cocaine dealers which my building has—if I had the choice I'd move to {name of a housing development} if I could or behind {shopping mall} where all those handicapped people are. That would be better for me but I can't do that cause I haven't got the power.

The second aspect of support that was reviewed critically by the participants was the role of the support worker and professionals. As stated earlier in this chapter, consumers did perceive some contacts with support workers and professionals as extremely beneficial, but there were also some significant issues raised. One issue was based on systemic flaws in the supported housing system with respect to increased caseloads for the individual support workers. Some people felt that their support worker's caseload was too high, and they felt unimportant at times when the workers were not able to meet expectations.

As far as SIL {supported housing program} goes too, sometimes it's difficult, something will come up and it's really hard cause your worker is busy already. And have like umpteen different clients to deal with. But maybe your dealing with something that is an emergency type situation.

She said she was kept late by another patient, well could she not, no matter how distraught that patient was—could she not have said just one minute, I'm going to give you more time but I have to call my next patient.

I think they need more SIL workers, especially in a community this size. There should— half the time when your worker comes over for your appointment with her and she helps you clean your house or something, she's got to leave early because of someone else or she gets there late because of someone else. Or not at all sometimes.

Some of the people disclosed that they had difficulty staying connected in a relationship with a support worker since there was an extremely high turnover of workers. The support workers are employed through the non-profit agency which is contracted to provide individualised support to individuals through a mutual agreement. I was a support worker for a supported housing program and left my position for another because poor wages were not congruent to the demand and responsibility of the position. This may not be the only rationale for high turnover, but the systemic undervaluing of support workers was a significant reason for me to reconsider my role. Many workers may choose to leave for a variety of reasons, but this has significant implications for the individuals in the supported housing program who have historically had difficulties in building relationships with paid staff.

I keep getting different ones and you don't know them. It's sort of strange walking in and saying were is my worker and being told that she is now someone else and you don't even know.

I wish they would stay put, I was supposed to get {name of worker} back, I get used to one person then all of a sudden I get someone else.

[Angry tone referring to a support worker who was delayed due to workload] We are humans---I understand that, but when I undertake a job I hope that I always take is seriously.

A third issue centred around disagreements with the program criteria. The criteria for most supported housing programs in British Columbia are set by non-profit agencies and professional staff from community mental health centres. Some predetermined criteria exclude consumers who may benefit from supported housing and desire a place in a program. Consumers within the consumer/mental health community continued to feel powerless on occasion.

> [When asked what would you change if you had the power, the participant responded] I'd change that {partner} wanted to get into the semi-independent living program and they told him they couldn't because he wasn't in a boarding home. I found this wrong that he should because he is handicapped, he should have been allowed to be in the SIL program too.

A fourth issue related to the time limits that one could continue to reside in the supported housing program. It was unclear if any of the participants had known anyone who was asked to leave a supported housing program due to a time limit, but one participant perceived that the stipulation was placed on them.

> I don't know, I just really feel displaced and it's just kind of contradictory that they would offer this place, and the ability to be somewhat stable financially and physically. And then want to get you out of that as soon as possible…So the whole thing is pressure, pressure. I don't know about most people but pressure is something that aggravates my illness.

Another issue revolved around actual interpersonal difficulties with support workers. On occasion some individuals perceived that they received negative feedback from a support worker without an adequate foundation of trust in the relationship.

> Yes, they have got to have tailored their responses accordingly until we get stronger to take a harsher critical analysis placed on us.

> You know that, back off when they need to and get analytical when they need to, and see that you can take and things like that. You need real genuine analysis, you can't have pandering but you need backing off when your distress level gets too high.

The consumers perceived that they would be receptive to feedback once some trust had been established. However, one individual felt that they received some feedback from their support worker that was not accurate, which hindered the relationship.

> I wish that people would just---like staff members would just come out and not be that way. You know say [change of tone] I understand and blah blah blah. I can spot that a mile away when that's false and I don't appreciate it...I would like to see less---what is it called when you agree with somebody just so they don't make a fuss.

All theparticipants did attempt to look critically at the power that support workers and professionals had in the lives. It is somewhat ironic that consumers continue to be oppressed within the context of the consumer/mental health community, since this is the community with which the participants identified. This influence over their lives came in many forms ranging from subtle suggestion to overt oppression. Many consumers' experience of oppression and control began prior to placement in a supported housing program.

> When I was in a boarding home they {the staff} degraded you all the time, they put you down when you couldn't get a full time job so they were being really strict if you didn't go along with them. They would treat you like a child doing wrong and being grounded. They did that so my friend and I decided to move out because it was too tough living there with them.

When asked who the most important people in their lives were, many people identified with professionals. Even if professionals or workers choose to not acknowledge their influence or power, it is inherent in their role with a group that has less power. When people with psychiatric disabilities choose to acknowledge people in positions of authority as important above others in their lives, this suggests the influence that professionals and support workers have.

That's about it for me, it was always people in authority like teachers, doctors, counsellors. I don't know why but they were always the ones that seemed the most important to me.

The gradual effect of a professional or support worker on an individual could be as basic as creating doubt in somebody about their own abilities. The participants explained that the support workers and professional were credible people who offered feedback, but this may have a negative effect if it creates doubt, as the following excerpt of a person discussing their internal dialogue indicates.

See that's part of the problem, they probably think that I won't join nothing. That's probably what it is. I don't know, I guess it goes both ways, they'll probably think of it as I won't join nothing. It's a tough question because they are right on that part, they know that if they don't say anything that nobody will go out or do anything. I don't know, sometimes your moods control how you feel and you don't feel like joining anything and other times you think that this sounds interesting and without even being asked you just go on your own.

For some consumers, their interactions with their worker could be detrimental if the worker stated opinions that reinforced a sick role. If there are expectations from a worker or professional that an individual perceives to be unrealistic, they may have a tendency to focus on predicted failure.

My worker is kind of lost in her optimism and keeps yacking it up about me going too work and its' just not going to happen. And I've told her that, and its' like she doesn't listen you know. And there is a time for optimism and its' great and it gets people motivated, but there is also a time for realism. Her doing that just reinforces how sick I am and the fact that---I mean I don't know.

Most of the consumers also recounted experiences where they perceived that their support workers or the professionals in their lives, limited the opportunity for choice and self determination. Many of the suggestions for activities are offered by workers within a context of

power imbalance, thus the individuals in the supported housing program perceived that their own

alternative suggestions or perceptions were less valid, or not worthy at all.

> It depends on your therapist too, because my therapist is very tough, very tough, he likes to be involved in everything.

> Well, sometimes being on the program I feel that they are always telling you what to do, like telling you to join this and you should join that. I kind of with that they would leave it up to you to become independent and do it for yourself.

> I guess most of it all comes from the therapist. He is usually the one who makes all the choices.

> ...she doesn't trust my opinion of myself and that's wrong.

> [Would you attend an activity if given the choice?] Not really, sometimes I feel like they are just saying it because I don't have my own thoughts or I don't know, it's hard to explain. Even if they don't remind me I probably would still come because I like to come to it.

Some individuals lacked confidence in choosing activities that promoted their well being.

Individuals also noticed that workers and professionals occasionally had goals for them to

pursue, that were based on the worker's judgements and excluded the desires of the consumer.

> Who's definition are we going to go by anyway, her definition of my being able to work or my definition of being able to work.

> And with her ---with my worker--- forcing those ideas on me about working and stuff, it keeps me up nights, I worry.

> I'd think that the proof is there that if that person is presently keeping themselves satisfied with their situation then that ought to be enough to show those people that they can't do anything better about it.

One of the individuals spoke about his/her implicit fear of the workers and professionals

in her life. She/he was extremely apologetic for negative remarks towards workers and

professionals, and believed that she was indebted to them for allowing her to have a position in a

supported housing program. She believed that she should resist in opposing the beliefs and

perceptions of the workers, which illustrates her understanding of the power inherent in their

position.

> But I always feel that I shouldn't stand up for myself because if it weren't for them I wouldn't be in this program.

> Yes I like them to come over and talk about things but I wish they could tell you less what you should join. I don't mean to sound mean or anything.

> I'm always afraid that if I don't do what they say--- because sometimes there are some things that everyone doesn't like to do like baseball or something. Not to put everyone down or anything, I know that they are trying to do it for your benefit to help you but sometimes---.

Finally, there were specific experiences shared by consumers that highlighted their

feelings of powerlessness and oppression within the mental health/consumer community. Some

of the participants' statements illustrated how some workers and professionals had disregard for

their personal perspectives. They spoke of situations where they experienced explicit oppression,

and encountered fear from those events in differing intensities.

> And it usually is not like they say join baseball and I go I'm not interested in baseball, and then they say well just join it anyway...

> Yes, like my therapist said to me last time I saw him "next time I see you, you had better have joined two new things" and he puts you on the spot and you don't know what to do.

> It's hard because you want to agree because they are in charge {professionals} so you kind of have to do what they say, but sometimes you don't agree with it.

> It makes me feel more afraid and more depressed because I know that I have to go through with what they say, and if I don't I'll be kicked off of the program or something.

> Then I had a psychiatrist that controlled me.

<u>LOSSES</u>

All of the consumers who participated explained that they had been excluded from, or had difficulty accessing different communities. Some people indicated how they felt distanced from their family community, and others depicted how they experienced stigma and overt resistance from the geographical community that inhibited belonging. Most of the effects were losses in some form or another.

The individuals did not blame their families for their psychiatric disabilities but perceived that they were misunderstood which created distance rather than closeness with their families.

> [Important people in your life] I guess my family, but they're kind of a distant figure looming over the horizon.

> Sometimes your family doesn't really understand and they don't know how to help you and sometimes when you have some kind of psychiatric disability, usually your family tends to move away from you more I noticed. That's what happened to me.

> My mother was really afraid of me when I turned sick. She didn't know how to take it, but she had nothing to fear because I was never violent

> My mom for example, she should have been the most important person in my life but unfortunately she's not because she doesn't really understand about my OCD (obsessive compulsive disorder) and things like that.

A few of the group members discussed how they perceived that it was difficult for them to belong to virtually any community. They perceived that belonging to the general community was out of their control.

> [If you had the power what would you change] Not at all, I'm feeling that it's the complete opposite, I'm not in control. I feel like I'm very out of it {belonging to the geographic community}.

> [What would you change?] Yes, like that, that would be something that I would like, and also the sense of belonging, like you have a job and career, and you belong like everyone else in society.

Little things like that, my problem is that I never get myself belonging to things. I don't know what it is, it's easy to think about but I never go and do it.

It appears as though many individuals do not understand the reasons behind not belonging to the geographic community.

However, the discussion in the groups did centre on the external pressures that promoted their personal losses. Some individuals explained that they felt misunderstood by others in the geographic community, and this led to a perception that they were perceived as less valuable.

...because when you deal with people that are in a secular world, that don't have a mental illness, they usually don't understand or take the time to understand.

So it is a mystery to me but I have the feeling that they have said "Oh { own name} has a mental disability and she is on welfare and we have to patronise her, or we have to not put much credence in what she says".

The one thing that I noticed about {name of community where individual resides} is that if you have a mental disability, you walk through a mall for instance and some people give you dirty looks because they know you have a mental illness and you figure you know, I'm just as good as you.

Yah but it is also like you said {responding and supporting another group member who talked about the negative impact of other's perceptions}, it's the attitude that is still out there that is part of the picture

A couple of individuals made statements that illustrated that they had perceived overt non-acceptance.

How would I describe my community. Really fast moving, I found that I could make friends easier here than I could in {former community}. But like {another group member} said, people that do have disabilities---they seem to snub them.

[And when you can't get along with people is it your own doing or do you think it's something else?] No it is their attitude toward my illness, like when I tell them I'm this way, I'm schizophrenic.

Some of the participants explored how stereotypical beliefs created an environment in the geographic community that lead to exclusion and oppression. Some preconceptions by others in the general community increased fears about people with psychiatric disabilities.

> And then she {person at church} said " Oh no that is not right" she said "the devil wants you to take those pills and the devil wants you to get stoned".

> I remember that I had a pastor tell me that all mentally retarded people are demons possessed. I don't quite buy that.

Despite their comments about societal stereotypes of individuals with psychiatric disabilities, the participants also had some preconceptions that resulted in losses. Some of the group members explored their loss of normalcy because they required medications over a lengthy period of time. This individual perceived himself/herself to be something other than normal.

> See there is not much I like to change right now but if I had to change things I'd like to be normal for a change. I'm counting on all these pills to keep me stable and keep me functioning---you know I'd love to live without them but I can't.

Some of the group members disclosed how they attempted to conceal their disability and their use of medications from others in the geographic community. Their desire to obscure their experiences from others in the geographic community does indicate their loss of identity as individuals, since there was pressure to conform to the general community's standard.

> [about intolerance] Not really per se but it is just a feeling---just a feeling I get. Maybe it is because I have a mental disability and I haven't rally talked to too many people about the fact that I have it. We tend to keep it to ourselves unless it's talking to therapist or psychiatrist or an MD.

> The only way that they could find out about the illness is if they catch you taking your medications then they ask you what is this for. And you have to tell them.

> I was trying to take my medications slyly and she seen me and asked what is that.

> Well you know what, I don't tell anybody about my mental illness. I don't.

When the individuals discussed loss of normalcy they also explored their loss of health and well-being. When the efficacy of medications was explored, one individual indicated that although he/she experienced adverse effects he/she continued to use them. This individual continued to use a medication despite adverse effects, which does represent loss of control over their health and well-being on some level. When asked what would they change if they had the power this individual responded;

> They have side effects and the doctor has been noticing the side effects now and have been changing my medication and taking me off other medications. Well if I had the power I wouldn't take any medication at all but I know I have to. It keeps me really stable and calm.

One group discussed how the psychiatric disability has made them *sick.* This indicates their loss of health or wellness, and people in the geographic communities tend to disregard individuals who are sick. They discussed how their disabilities affected their lives when they responded to the question [If you had the power what would you change?].

> Well I would definitely change---as far as my illness goes---not having an illness.

> Are we talking absolute power or omnipotent power? Cause I wouldn't be sick if I had the power.

> I don't know, this illness has got---like it effects everything. There's no one area of my life where I can feel comfortable with that the illness has not touched.

Some individuals also addressed their loss of stability with respect to having a psychiatric disability. The instability interferes with many aspects of an individual's life, including their full participation in their neighbourhood and involvement in the consumer/mental health community.

> And it's like I have some brains that I could maybe use but then their use is inhibited by the effects of say the depression. It makes you have an inability to concentrate and stuff

like that.

...I've been coming to the clubhouse in spurts, I show up for a few days and then I won't show up at all for a few weeks. It's this instability that I would like to change.

It's okay if once in a blue moon if you feel down, that's OK. But with me its'---it could last weeks---that's why sometimes I haven't been coming to the clubhouse.

As with most experiences of loss, members in one group discussed the importance of coming to terms with the experience. For a few members, they recognised the loss of their health and attempted to discuss their experiences with others in order to gain control over their lives.

Because I think, well personally it took me a long time to come to terms with the fact that I have a mental disability so I wasn't too---I didn't really find that I could talk to other people about it too much.

But now that I understand my illness and ---I find it easier to live with and I find it easier to live in the community.

Many of the individuals discussed how they desired a vocation in the general community and perceived that they would never acquire a position. During this portion of the discussion they were sharing their loss of a meaningful work role as it is defined by society.

[What would you like to belong to or have?] I guess to have a place in society, to have a career and have your own work space, something that you know is yours and that you go there everyday.

Yes somewhere that you feel you are somebody, you feel like your important in that career.

The consumers talked about how they had participated in the workforce in the past, after the onset of their disability. This indicated that as a result of their work, they had some negative experiences that diminished hope. They explained that they worked in demeaning jobs and were employed for wages that were too low for subsistence.

But I made a promise to myself that I would never work in a menial job again…

You can't support yourself on those jobs. It's impossible. And a lot of jobs now are part time.

One of the group members spoke about his/her apprehension with respect to working in the geographic community. If one has not worked for a long period of time or they have worked in a sheltered environment they begin to doubt their skills.

But out there in the quote unquote real world it might be a little harder to---for us to cope. …this clubhouse is not a model of society and it is not the same. The work that I do here is not work that I could do out there. It maybe has---it coorelates with some factors of it but by and large it is not the same.

The consumers in all of the groups did discuss how their inability to access employment in the geographic community had other negative impacts. They perceived that they were viewed negatively by members in the general community because they were not employed. When they perceived that they were not viewed as worthy members of the community it created guilt and shame. The consumer's guilt and shame was produced by how they believed they were viewed by citizens in the general community. When the consumers experience the loss of a work role they also lose their ability to be seen as productive and valuable to the geographic community, because they perceive that they are excluded.

I would tell people my problems and I would be shunned, and ridiculed or just considered lazy, no good, unproductive and things like that.

Especially wherever I go people say do you have a job and I say no, and they say how come an I really don't want to tell people that I'm depressed and that I have OCD. But, around my family they think that people with OCD and depression should just snap out of it and get on their feet and support themselves.

Some people, they'll speak a little platitude and say well your a human being and just because you can't support yourself right now blah blah blah…

A couple of the group members also experienced the *poor bashing* rhetoric that is prevalent

within the discourse of community conversation. Many individuals in neighbourhoods perceive

that people on social assistance are to blame for their social position, rather than systemic and

environmental/structural factors such as institutional oppression. When people are blamed for

their social position they lose some power and internalise their struggles.

> {on guilt} [Is it the social culture projecting that onto you or is it something inside you
> creating it?] It's probably a bit of both. Because I hear oh we pay too many taxes and
> what are these people doing, they're not working, but maybe part of it too is the self
> esteem gets so bad.

> {Perception projected on people who collect social assistance} You're a bunch of
> freeloaders.

> And also there are people---always a big fear over welfare fraud. And every time I hear
> about one of those stories I feel guilty. Even though I'm not currently frauding the
> government—defrauding, whatever.

When the community view individuals in a negative manner, they begin to view themselves less

worthy of receiving support. A consumer in this study explained that they felt less deserving of

getting support from the mental health community. This also indicates a feeling of a loss of

worth.

> Feeling worthy of this beautiful big clubhouse with all these wonderful things in it and
> these staff. I mean I can imagine that it costs quite a bit of money to run this place every
> month and why do I deserve to get free money handed out by the government.

> I'm humanitarian too but when I personalise it I have a real problem with it. What the
> hell---why do I deserve this you know.

Another loss that the group participants had experienced centred around social

connections. Many of the group members discussed their limited connection with other people in

their lives, and most had few or no social connection with individuals in the general community. Some individuals explained how they had lost their social ties with people in the general community, and others explained that they never had any, but desired the connection. For some consumers, they insidiously lost their social ties with people in the geographic community without any concrete rationale.

> I used to go out to nightclubs and stuff like that and make friends. My life is not fulfilling to me, some people enjoy a quiet life where they don't really have many things on the go and I think in relation to how I used to be when I wasn't quite so sick.

> Like there's a whole culture that I wish I could still involve myself in and I just can't because I haven't got the motivation.

Some consumers described experiences where they lost social connection due to misperceptions about psychiatric disabilities. One individual used one word (**jaded**) to depict the experience of losing a friendship with someone in the general community because they did not understand the disability. Other people in the same group, and other groups, spoke of similar experiences.

> We got along well but when my disorder was there she couldn't really understand it. Sometimes she would laugh and I would laugh too, but I could tell that she really didn't understand it.

> It's just hard to find---first of all friends that understand maybe about this problem you got...

> I used to have tonnes of close friends, now I have no real close friends anymore.

> I have emotional problems too that kind of keep me from maintaining close relationships.

Some of the participants long for connections to the other people in their community who are not members of the consumer community. When asked how they would define community, most of the participants excluded the geographic community from their responses. However, when asked what they would like to have or belong to, many individuals desired a connection to the

geographic community, and for some, this desired connection was social in nature.

> I'm speaking in relation to people who have gone through high school together and they still stay friends outside of high school. I would love something like that where you knew the people for so long and you were just like family. That would be really nice.

> Possibly belong to a social club of people who have abilities or disabilities and people who are normal. Mingling and intermixing.

IDEAS PERTAINING TO COMMUNITY CHANGE

The participants did view the concept of community as a dynamic, not static. Furthermore, some of the group discussion was directed at suggesting some changes or strategies that would benefit themselves and other people with psychiatric disabilities with respect to building community. One participant explained that there are more similarities among people than differences.

> You know they have times when they're not completely in control either but I'm under control most of the time so I just like to show that we are normal, we are humans you know. We have nothing to be ashamed of.

Most of the consumers explained that they needed to be heard in order to change the geographic communities where they resided. They needed to emphasise the strengths and value of people with psychiatric disabilities.

> We've got to fight for them. Or at least not fight but actively engage the world in the dialogue that at least discloses our grievances and our---what we find pleasure in.

> Well there are many who need to communicate something in whatever form. And I want them {other consumers} to---their voice, on their terms to be heard.

People in the geographic community and individuals in the consumer community share many similar perspectives on development and human growth. Many people have a desire to be *normal*, although this framework is not concretely defined. One of the group members struggled

with the dichotomy of understanding that he/she is not *normal* by society's standards, yet he/she was driven to achieve personal potential and fulfilment.

> My goals are mainly less absolute. I'm determined with the fact that I have an illness. I have many of the potential---I only developed because of the drive to become first of all normal, but then just the best I could be.

Some of the participants talked about hope for the future during some of the discussion. If consumers had the opportunity to realise their potential then they would have hope with respect to their well being in the future. One of the participants mentioned to another that there was hope about the future for other consumers since he/she had positive experiences in the geographic community.

> They can survive and things do get better so they'll get even better. It will get better for you {advice to another participant}. Never give up.

Participants in the groups also discussed having a valued work role and the impact that this would have on building hope and realising their potential. One of the means described by a group member centred around their support of other people with psychiatric disabilities. This was viewed as valued work intrinsically since it did not carry a monetary reward in the current system. They suggested that this was a means to justify their social assistance and went on to mention that it ought to be developed into paid positions that are acknowledged in the geographical community.

> I'm also an effective---effectively working, if you accept my definition of work for the money I'm getting. By just supporting people, I'm redeeming their stigma and so forth.

> What I'd like to do is work in the system among my people. They know me, we can work well together. I'm the kind of person---people can identify with and if he got paid for being a supporter of consumers and things like that.

During all of the focus groups, the members did also have discussion about concrete strategies that could occur, or have occurred, with respect to creating community changes in the best interest of people with psychiatric disabilities. One of the skills mentioned as necessary to change was self advocacy as an effective communication tool. A couple of means to communication were discussed.

> Well I know from going to the mental health centre and seeing how much information is being published in the forms of pamphlets or brochures on the racks. I know that there are symposiums or conferences or things of that nature in the community just to make the community more aware.

> Well, I think you would have to use the media because so many people watch TV, cable TV or regular TV, and listen to the radio. I think you have to put more commercials on TV, that would be expensive but it's worth it I think.

The individuals in the study also spoke about a personal role they could take with respect to advocacy and creating community change. Improved interpersonal communication skills was identified as one of the essential components to individual advocacy by a group member currently involved in advocacy and community education.

> I have communication skills now, it was only a potential before, it was a jumble of images in there, I didn't know how to get them out. I had a drive to communicate, I needed to tell my story.

Many of the consumers who chose to participate in the study explained how they had told their personal stories in a manner that could alter the perceptions of people in the geographic community. Stereotypes exist because of misperceptions, thus consumers could influence people in neighbourhoods to be more accepting if they shared personal stories. Some of the participants explained that they are in control of their lives which is paradoxical to the perception of many individuals in neighbourhoods who believe that people with psychiatric disabilities are out of

control.

> But I don't mind telling them. I like to dispel the stigma against mental illness, I've got it pretty much under control and when they see a person that has it more or less under control as good as most normal people.

> People are under control as we know, they're no more under control {in the general community}.

The geographic community does gain insight through listening to the personal stories of consumers/survivors. When the people who are most affected by a disability educate others, the process is empowering and fulfilling.

> {One group member speaking about another} But I think it is starting to change, you know [name] is a good example. Because he does go out there and he does educate. I've been doing a bit of that myself. I hope it makes a difference.

> It has made a difference among the people that I talk to in colleges and universities. They come up to me and they said thank you very much---and each member in the class has signed a card thanking for the insight and education that they got from the whole partnership.

Some of the focus group members suggested that their stories were more easily received if they explained the biological nature of their disability. It seems that explanations based on biology may limit the opportunity for others in the general community to view psychiatric disabilities as character deficits. At least in part, the behaviour of individuals who experience a psychiatric disability could be rationalised through genetic factors. However, people with biological disorders are not exempt from oppression within the context of geographic communities. It is possible that consumers who focus on biological explanations perceive that the community is more accepting of behaviour if it is linked to biological disease. Perhaps they would receive less stigma if their behaviour was founded in physiology and not personal choice. Many of the participants did state that they disclosed their personal stories within a biological framework.

I'd like to stress the whole neurotransmitter thing, cause you can't really dispute that…in the past it was much like that where people would be like ewwww, go away from me you're crazy or something but now I just explain how it is chemically and nobody---they can't really dispute that you know.

So you know it's funny, I just bring science into it and say well no it's actually because this does this and them it prohibits this from doing that and blah blah blah.

And I told her that schizophrenia is a real disease---it's a biological disease, it's corrected by pills and they shouldn't say stuff like that. {responding to a stereotype}.

Participants also discussed their need to talk about the experiences of living with a psychiatric disability. They felt that there was a need to move away from being silenced to a position where they could share their realities to facilitate education in others.

[People won't understand] …unless they have a relative or someone they know that already has a mental illness.

My mom had a breakdown when she was about seven and it was all very hush, hush, but I think I would continue to change people's attitudes and educate people more.

Having more dialogue, more conversations between people who have abilities and people who don't {referred to consumers as people without abilities}. I think that people are afraid of us.

There was hope that educating the community would have a positive effect for consumers despite the negative interactions that many of the group members had experienced with others in the general community. Discussion in at least two of the groups supported the notion that the general community is open to listening to information about people who experience psychiatric disabilities, and may even become supportive with some education.

And those are the people, when we change their minds—they will make a difference in how we are treated. Because they will be the ones doing the treating and standing up for us among those who don't treat us quite right.

I think it's difficult to change things overnight but I think if a person is open to learning about a person who has a disability then I think that you can influence them. But, I think

that the person themselves has to make up their own mind that they are going to change their attitudes.

Participants perceived that people with psychiatric disabilities could have a role in changing perceptions of other individuals who reside in the general community. People with psychiatric disabilities need to mentor, and support other consumers so individuals can acquire and feel confident with their communication skills. The individuals in this study believed that there is hope that they could make positive changes in the community by sharing their stories and experiences within a context where they would be heard.

CHAPTER 5
DISCUSSION OF THE FINDINGS

The goal of this research study was to explore how people with psychiatric disabilities who reside in supported housing define, and participate in community. In this chapter, the findings will be related to the current literature; the limitations of the study will be explored; and the implications for social work will be discussed.

FINDINGS RELATED TO THE EXISTING LITERATURE

During the review of the literature a precise definition of community was difficult to ascertain. Furthermore, a definition based on the perceptions of people with psychiatric disabilities was not found. Participants did provide information about their perception of community within the context of this study, which resulted in some diverse descriptions. One of the issues that was explored by the participants centred around belonging and being supported by others around them. Aubrey et al. (1995) discussed the concept of neighbouring which is defined by people who live in close proximity, and engage in relationships that share reciprocal support. One of the participants explained how he/she engaged in reciprocal relationships with other consumers that were supportive in nature. (Aubrey et al. 1995; Weil 1995) elucidated that belonging to a group was also an aspect of community that was important for people who experienced a psychiatric disability. Many of the group participants communicated the importance of belonging to a group, and the resulting benefit that this had with respect to well being. The findings did support that the participants perceived that belonging and reciprocal relationships were important in terms of defining community.

Some researchers in the field indicated that people in supported housing were more lonely and this was not due to the housing itself (Livingstone & Srebnick 1991; Hatfield 1993), but due to the resistance of the geographic community. The findings indicated that there are barriers to community which will be discussed later in this chapter. However, they also discussed how their consumer/mental health community reduced isolation and provided opportunities for participation. Most of the consumers in this study were not lonely since they were included in a community with others who experience a psychiatric disability, and the workers paid to provide services. Consumers being supported by a community of their peers is also a fact (Wilson 1996; Francell Jr. 1996). Other people with psychiatric disabilities may be the most suitable candidates to provide support and promote wellness due to their life experiences. However, the individuals in this study also explained that support workers are also an integral component to their consumer/mental health community. Some participants perceived that the support workers understood them better than their family community. They also believed that the workers supported them out of care instead of obligation.

It is difficult to decipher whether professionals and support workers are important because of their role, or due to significant barriers that decrease involvement with other people in the geographic community. Regardless of the rationale, most of the individuals who participated in this study believed that they were valued members of the consumer/mental health community, and did not isolate in their suites.

It also appeared that the individuals who participated in the focus groups believed that they could share their wisdom and guide the discussion at times. During the process, some of the group members were connected to each other and I perceived that I was connected to them, which is a foundation of participatory research as indicated by (Hardcastle et al. 1997; Carling

1995; Mason & Boutilier 1996). During the process I engaged in reciprocal sharing of information and life experience, and the other people did the same. Participatory research is a community building exercise in itself, thus research with consumers is a function within the consumer/mental health community.

The findings reinforced some of the literature centred on the benefits of supported housing. The results in this study paralleled some of the projects (Carling 1995; Nelson 1993; Wilson 1996) which found that supported housing increased independence and self worth for people with psychiatric disabilities, which is integral to creating hope. One of the participants in this project explained that the support worker fostered hope when they worked in an egalitarian manner. The findings relate to Tanzman (1993), which indicated that a global definition of well being is warranted. Consumers/survivors have historically been referred to as well, or unwell, based on their mental status, and their environmental surroundings have been excluded. Tanzman (1993) emphasised the importance of correlating consumer's lack of material resources with their health and well being, rather than the increase in pathology. The participants in this study discussed the importance of stable and affordable housing to increase security and independence. They also discussed the benefits of receiving rent subsidies and an increase in disposable income.

Many of the participants had insight concerning their difficulties in the community, and had ideas with respect to positive change. Runyan & Faria (1992) explained that the community cannot be ignored if people with psychiatric disabilities are to be integrated into the community. The consumers in this study reiterated the notion that they should be involved in educating the community through sharing their life experiences since this will facilitate a connection to others in their neighbourhoods. However, most of the participants disclosed that they are more willing

to share their disability from a physiological perspective since it will be received as more *normal* to others in the general community. The consumers did not take a critical perspective in regard to presenting their disability as flawed physiology. It seems as though the geographic community continues to oppress consumers by dictating how information will be presented to them. It appeared that in order to be heard, the participants had to explain that their disability was not psychological in nature.

Furthermore, the findings sustained that people with psychiatric disabilities who reside in supported housing continue to be marginalised in the geographic communities where they reside. Aubrey et al. (1995) explained that neighbours felt seventy percent sure that they would have contact with others who resided in geographic proximity, but most were unsure whether they would have contact with a neighbour who experienced a mental illness. Many of the participants in the study felt that it was necessary to conceal their psychiatric disability from people in the geographic community and were fearful of the consequences if they were discovered.

Some of the consumers in the study explained that they felt guilty about accepting support such as financial, housing, and perceived that this was caused by other people in the general community who viewed them as lazy or incompetent. This correlates closely to Mullaly (1993) when he illustrated that marginalised people often internalise oppression into self blame. It appears as though Lord & Dufort (1996) are correct in their assertion that people with psychiatric disabilities could gain power through avoiding the victim blaming rhetoric by re-centring their analysis on the environment.

Carling (1995; Aubrey & Myner (1996) conceptualised the community integration model for people with psychiatric disabilities. Reidy (1992) also discussed the importance of consumer participation the general community. This model situates consumers in the geographic

community, but not on the periphery. Within the context of community integration, people in supported housing would also have meaningful roles and relationships with other people in the general community. Within the context of this study, the participants desire to achieve the principles of the community integration model, but perceive that they are not able to access meaningful roles. Most of the participants explained that they were rarely able to participate in the geographical community in a meaningful manner, thus they perceived themselves to be less valuable to the community, and had few or no relationships to others in the geographic community where they resided.

Most of the people who were a part of this study explained that the practice of mental health professionals and other mental health workers had been positively altered in the past years, but continued to have significant shortcomings. In some of the individuals' experiences, their workers espoused practice principles where they viewed consumers in terms of their strengths, capacities, and resources, rather than deficits and pathology. These experiences of receiving services was similar to the practice principles that were illustrated by (Tanzman 1993; Weick et al. 1989).

However, the findings suggest that the mental health system in the communities where the participants resided did not meet the standards set by some researchers in the literature and the British Columbia government. In the Strategic Mental Health Plan for British Columbia (1993) people with psychiatric disabilities were to be provided with more choice and control over supports and service to foster holistic care. Wilson (1996) also illustrated that consumers should define their needs and how they ought to be met in a health care system. Some experiences of the focus group members was contrary to these methods to holistic care and well being. Most of the supported housing programs in British Columbia are controlled by community mental health

centres, and non-profit agencies contracted to provide services. There is relatively little input from the perspectives of the people with psychiatric disabilities. Some of the participants in the study perceived that they had little choice within the context of planning and treatment with respect to the supported housing program. None of the participants were involved with planning, or policy making, at any level. It appears as though literature by Jane Melville Whyte (1996) was valid when she explained that professionals in the mental health system are unaware, or minimise the effect of their power and privilege. She stated that "oppression is a side effect of treatment" and the participants corroborated this experience. They perceived that they were oppressed through a range of behaviours, from subtle suggestion to overt control.

LIMITATIONS OF THE STUDY

The information in this study was generated from the participants through their words and experiences. I intended on providing information from the standpoint of people with psychiatric disabilities who resided in supported housing. The consumers who participated took the opportunity to share their experiences of community, and I attempted to honour their wisdom by sharing their perspective. However, this study also had some limitations that impeded the generation of information. The data collection method that was chosen caused the loss of context, power imbalance remained between the researcher and the participants, and the focus groups were small in size.

Firstly, the focus groups were audio taped and transcribed from the cassettes. Some memos were recorded after each of the groups but some of the context was lost without the use of videotaping. Videotaping was not selected due to its' intrusive nature, but some information about the group dynamics was inevitably forfeited.

Secondly, two of the three focus groups had only two participants, which created a reduction in the group dynamic. In both of the groups, the participants had a prior relationship which increased the likelihood for conformity and censoring, although it is believed that this was limited due to the diverse responses in each group when the participants continued to voice their individual perspective.

Lastly, a power imbalance remained between myself as a researcher/professional and some of the consumers who participated. I attempted to equalise the power through pre-group explanations and offering compensation for participation. However, some of the participants attempted to apologise for responses that I could potentially perceive to be negative, and they occasionally requested some feedback from the facilitator to substantiate their responses. Some individuals attempted to ensure that their responses were *correct* and acceptable to the facilitator with a statement such as "I don't mean to put anyone down…" as an example.

IMPLICATIONS FOR SOCIAL WORK

As the facilitator of the interviews, it was a learning experience. As a result of the study and the information generated by the consumers, I learned a great deal, both personally, and professionally. The participants shared their perceptions of community, and this information was beneficial to me as a researcher, but equally invaluable, as a practising social worker. The results have implication with respect to social work/mental health professional practice and future research.

More Research

The experience of this qualitative project allowed me to view research in a different perspective. The process of research can be empowering for the participants if the method allows. Participatory research is therapeutic and community building in itself. The participants gain connections to others, and through the group process gain a greater understanding of themselves and the environments in which they live. The participants also have the opportunity to develop skills, be connected to the community, and have a valued role (Carling 1995). Research within the domain of social work ought to have a participatory method to allow for the involvement of marginalised people. When consumers are acknowledged for their experiences and skills, their lives are improved (Mason & Boutilier 1996; Park et al. 1993).

Since this study was exploratory in nature, and the review of the literature did not find similar studies, further exploration is needed. Future research could focus on changes needed to supported housing, the qualities of the consumer community, or many other areas that were discussed in this project from the perspective of people with psychiatric disabilities. This project is not a foundation in discovering consumer's perception of community, but it validates the importance of exploring the context of community from the standpoint of consumers and other people who are oppressed.

Practice with Individuals

The findings indicated that there are changes required for practice on behalf of social workers and other mental health workers. Individual work with people who experience a psychiatric disability is complex and warrants critical analysis on a regular basis. How do professionals support and promote self determination in the people that we work with? If social

workers and other practitioners are to value self determination they ought to behave in a manner that demonstrates those principles. People who are employed to work with consumers in a supported housing program must allow for choices and be open to alternative perspectives provided by the individuals in the programs. Many of the participants in this study perceived that they had no choice with respect to participation in the supported housing program, and also perceived that goals were established by professionals or support workers on occasion. It is fundamental that social workers view consumers in terms of their capacities as individuals, and not their deficits as disabled people (Carling 1995). The practice of working with people with psychiatric disabilities has evolved. Consumers were once viewed as patients who were ill and in need of institutionalisation. Then the patients began to be viewed as clients within the context of rehabilitation after the process of deinstituionalisation. Mental health workers must now face the challenge of working with clients as citizens, each having equal value when compared with any other individual in the neighbourhood.

It is also important to view the dichotomy between professional and client from a critical perspective. The client professional relationship implies one where a client is in a passive or dependent role with a professional (Carling 1995). A couple of the participants discussed that their relationship with their workers/professionals was more egalitarian, based on human connection. It is feasible to expect that social workers practice within a framework where consumers are viewed as equals, and perhaps as friends and colleagues. Clinical social work has a function within the supported housing program for crisis intervention and skill teaching, but it is necessary for workers to expand on their skills to provide a holistic support. It is integral for social workers to understand the structural rationale for personal troubles and assist individuals into putting this into perspective to reduce internalised blame and guilt (Mullaly 1993). The

consumers in this study indicated that they experienced barriers to community participation that was not in their control, yet some indicated that they were not worthy, or felt guilty, for support that they received with respect to their marginalised position.

It is also essential that social workers and other professionals who work with consumers/survivors look critically at the power in their relationships. Throughout this paper, I have used the term consumer to identify the participants. However, only a couple of the individuals used the term when they self identified, and most of the people self described as patients, or people with mentally illness. Social workers in the field of mental health services in British Columbia have more power than consumers, given their social position, thus one must embrace the ethical dilemmas that professionals face daily. The language that we use on a daily basis sends messages to people we work with, and others who we have contact with in our neighbourhoods. It is possible that language can reinforce negative messages about people with psychiatric disabilities. We must also look critically at our involvement in all facets of a consumer's life. If consumers identify professionals and formal supports as the most important people in their community, that requires some questioning. It may be necessary for practitioners to separate ourselves out from the consumer community if we continue to utilise oppressive methods in support and have relationships with people who we have influence over. It is possible to remain separate from the consumer community, yet nurture and facilitate their connections with other consumers and groups of people.

We work with individuals that receive invasive treatments that have profound effects on the body, both negative and positive. In some instances, the individuals that we support will receive treatment against their wishes if they are committed to hospital under the auspices of the mental health act. These are ethical issues that effect the relationships that social workers have

with individuals who reside in supported housing.

Community Practice

From this project, it is discernible that the consumers in this study perceived that they did not belong to the geographic community. Many of the individuals perceived that they did not have a role in their neighbourhood, or relationships with the people who live there. Social workers ought to engage in the task of deconstructing "normalcy" in the geographic community. It is reasonable to assume that workers can encourage people in the community to change their preconceptions of normalcy which would allow consumers to have better opportunities for participation. Professionals that have ambition to be change agents and promote social integration for people with psychiatric disabilities will have to acknowledge and attempt to alleviate the profound sense of alienation (Carling 1995). The geographic community needs to be viewed as a resource where there are possibilities for awareness, inclusion, and acceptance, rather than for the obstacles such as fear, prejudice, and rejection that are present (Carling 1995). A mental health worker would have to move from developing supported housing towards a model where they develop, and build supportive community. There are a number of actions that social workers can pursue to attempt this undaunted task. Firstly, the community can, and has been reached through education. It is important that people with psychiatric disabilities be an integral component to the education by sharing their experiences to build community through creating connections. Secondly, workers should support and advocate for systemic changes. All of the participants spoke about their connection with the consumer/mental health community, and they also explained that they experience difficulty in accessing valued roles in the community. It seems that employment could be developed through using peers as supports for others who

experience a psychiatric disability. Through my employment as a mental health professional I am aware that peer support programs, as a funded alternative to traditional supports, are currently being piloted in many areas of British Columbia currently. Thirdly, it is necessary that consumers/survivors have input into developing the policy and procedures, mandates, and goals of the agencies that are providing services to them. It is essential that individuals be provided with responsibilities and opportunities for participation, and the act cannot be viewed as a token gesture where individuals are asked to participate, but given little credibility. Fourthly, social workers need to continue to be committed to advocate on behalf of many different groups of marginalised people. Systemic oppression affects many individuals in the community and resources are required that will positively effect people with psychiatric disability. Consumers require safe neighbourhoods with affordable housing, greater chances for employment, and a number of other material resources that most oppressed groups advocate for. The more one categorises consumers as a group in terms of resource deficiency, the greater the chance of alienating those individuals from other marginalised groups as well. Social workers can have a role in networking oppressed groups with each other to develop social connections. Lastly, social workers require comprehensive training where they can learn inter-agency or intra-agency advocacy skills to insure that consumers are connected to as many beneficial resources and people in the geographic community, which would promote participation and the building of social connections.

Clinical skills for individual practice and intervention are necessary for social work/mental health work in supported housing programs, but one also requires the skills and awareness to look at structural barriers that deter the involvement of consumers in the daily activities of the geographic community. Social work in the field of mental health must honour

the roots of community development and advocacy, in order to promote community integration

for people with psychiatric disabilities who reside in supported housing.

CHAPTER SIX

CONCLUSION

The goal of this study was to explore the participation, and meaning of community from the standpoint of people with psychiatric disabilities who resided in supported housing. The process of this study was meaningful to myself as a mental health professional and as a student. The participants in the three focus groups were the focal point of the information provided, and they shared their insights and wisdom voluntarily despite some valid reservations prior to discussions. The exercise of meeting and exploring issues was an effort in community building. The process of information exchange was reciprocal in nature, and the individuals in the groups also attempted to make me comfortable on occasion.

During the study, information was provided that enabled a critical analysis of the general community and agency practices which minimise the skills and talents that consumers have to offer. It also created insight about the value and merit of the consumer/mental health community with respect to supporting people, and offering valuable social connections that fuel development and nurturing. The discussions also validated some personal beliefs and values in regards to social work/mental health practice. Social workers ought to oscillate between individual practice and community development practice to provide support to people with psychiatric disabilities in a holistic manner. This qualitative study provided opportunities for me to become a part of the consumer community, and share perceptions and assumptions with others in a manner that promoted connections rather than differences and pathology.

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