

UNIVERSITY OF CALGARY

UNSPOKEN VOICES: THE EXPERIENCES AND PREFERENCES OF ADULT
MENTAL HEALTH CONSUMERS REGARDING HOUSING AND SUPPORTS

by

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ABSTRACT

In Canada, the mental health consumer movement is beginning to take hold. In the process, consumers are starting to indicate what it has been like to have a mental disorder, and how they have managed with housing, the mental health system and informal supports. Concurrently, consumers are demanding a say in mental health policies and programs that directly impact them.

This qualitative study presents the results of interviews with a self-selected sample of 20 adult mental health consumers from Calgary, Alberta. The study focused on two questions that had been unexamined in previous research: 1) what have been the experiences of adult mental health consumers with various types of housing and supports, both formal and informal and 2) what are their preferences in the areas of housing and supports.

Findings indicated the variety of types of housing where consumers lived and the factors associated with each type of housing that had both positive and negative impacts for consumer's mental health and life satisfaction. Findings also identified the types of supports and the dimensions of those supports that either assisted or interfered with the mental health consumer's recovery. From the results of this study, discussion and recommendations for mental health policies and programs, social work practice and education, and future research are also presented.

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TABLE OF CONTENTS

	Page
Title page	i
Approval page	ii
Abstract	iii
Acknowledgements	iv
Table of Contents	vi
List of Tables	ix
 CHAPTER ONE: Overview of the Study	 1
Significance of the Research.....	2
Purposes of the Research	3
 CHAPTER TWO: The Background and Literature Review	 6
Definitions	10
The History	11
Theoretical Underpinnings of the Literature	21
Biological Theories	21
Psychological Theories	23
Sociological Theories	25
Rehabilitation Theory (Psychiatric Rehabilitation)	30
Conclusions on Theory	32
Review of the Literature Regarding Housing and Supports	34
Community Housing in the Context of Community Supports	36
Research Related to Housing in the Mental Health Field	38
Synthesis of Findings	48
Conclusion of the Literature Review	50
Rationale for the Study	51
Research Questions	52
Summary	53
 CHAPTER THREE: Research Methodology	 54
Introduction	54
Qualitative Research Design	54
Sampling Procedures	56
Sample Selection Criteria	57
Accessing the Setting and Research Participants	58
Data Collection	59
Data Analysis	65
Trustworthiness of the Data	64
Credibility	65
Transferability	67

	Page
Dependability	68
Confirmability	69
Ethics	70
Conclusion	70
CHAPTER FOUR: Consumers' Experiences with Housing	72
Introduction	72
Demographic Profile of Research Respondents	72
Housing Moves	75
Experiences with Various Types of Housing	84
Rental Units	84
Room and Board	98
Rented Room	99
Group Homes	101
Approved Homes	107
Home Ownership	108
Homelessness	110
Summary	110
CHAPTER FIVE: Consumers' Experiences with Supports	112
Introduction	112
The Formal System of Supports	113
Factors Related to the Program	113
Factors Related to the Staff	123
Interacting with the Medical Community – The Physicians	132
Issues in Specific Areas of Formal Support	140
Stigma	156
The Informal Supports	159
Family Supports	159
Support of Friends	164
Summary	166
CHAPTER SIX: Consumers' Preferences for Housing and Supports	169
Preferences Regarding Housing	170
Preferences Regarding Formal Supports	174
Summary	186
CHAPTER SEVEN: Discussion and Conclusion	188
A Reconceptualization of Housing and Supports	191
Strengths and Limitations of the Study	195
Links to the Existing Literature	197
Housing Literature	198
Supports Literature	203

	Page
Implications for Mental Health Policy/Programs	206
Implications for Social Work Practice	211
Implications for Education and Training	214
Recommendations for Future Research	217
REFERENCES	220
APPENDIX A: Study Consent Form	233

LIST OF TABLES

	Page
TABLE 4.1 The Demographic Profile of Research Participants	73
TABLE 4.2 Respondents' Diagnosis	75
TABLE 4.3 Reasons for the Frequency of Consumers' Moves	76
TABLE 4.4 Aspects of Housing Leading to Consumer Satisfaction	85
TABLE 5.1 Formal Supports – Aspects of a Program Leading to Consumer Satisfaction	114
TABLE 5.2 Physician Factors Important to Consumers	132
TABLE 5.3 Specific Areas Of Formal Support	141
TABLE 5.4 Issues Related to Leisure Supports	153
TABLE 6.1 Consumers' Preferences Regarding Housing	170
TABLE 6.2 Consumers' Preferences Regarding Formal Supports	175
TABLE 6.3 Ways to Address Gaps in Service	178
TABLE 6.4 Preferred Employment Supports	181
TABLE 6.5 Preferred Financial Supports	182

CHAPTER ONE

OVERVIEW OF THE STUDY

Across North America, historically, mental health consumers had little say or choice regarding their housing or supports. Resources were limited, the professionals were in charge of the mental health system, and consumers were forced to take what was available or go without. For at least the past two decades and to a large extent today, community living for mental health consumers consisted of communal living in places like group homes that were transitional in nature and based on a continuum model of care. The services available in that living situation is what was offered to the consumer and, in some instances, availing themselves of those services was a requirement of a consumer living there. As consumers' mental health improved and they became more independent in their functioning, they were forced to move to a new place to live, that ostensibly would help them reach their full potential.

In the last decade, however, this approach was called into question. More recently, a model of service delivery that considers normal housing and comprehensive supports offered in the consumers' home or community is being acknowledged as a growing trend and an important direction to move in (Carling, 1995; Mechanic, 1999; Provincial Health Council of Alberta, 1998; Rutman, 1994).

Currently in Alberta, the government is reconsidering its housing and mental health systems. With a growing recognition of the importance of input from mental health consumers when rethinking these systems, currently, there is an increased emphasis on the involvement of consumers in the process of redefining mental health service delivery, which in Alberta is referred to as mental health reform. Consumers are being invited to take

their place on a number of committees planning for a revised and revamped system of housing and mental health services and supports. At the same time, policy makers and service providers are also considering what the research has to say when planning delivery of services.

Significance of the Research

Increasingly, research is being undertaken which specifically elicits information from the mental health consumer's perspective (Carling, 1995; Hammaker, 1996; Nelson, Ochocka, Griffin & Lord, 1998; Ridgway & Zippel, 1990; Tanzman, Wilson & Yoe, 1992). This is not to say that the professional voice or that of decision-makers is still not relevant. However, as Carling has emphasized, "the most valuable source of knowledge...consists of the wishes of people with psychiatric disabilities themselves...To frame needs in terms of what consumers want cuts short a great deal of debate involved in trying to reconcile the perspectives of various constituencies (e.g., professionals and families)" (p.141).

This qualitative study of adult mental health consumers in Calgary, Alberta, involved a systematic effort to collect information from them about their perceptions and experiences with housing environments and supports in the hope of gaining insights about what is required in this area. This is particularly timely as when the research commenced, the Provincial Mental Health Board in Alberta planned to shift, over a five year period, \$33.6 million dollars from institutional care into community mental health care programs (Otteson, 1995). Although a number of significant changes have occurred with the Provincial Mental Health Board since the study began, the direction of service provision and the concomitant budget have not been fully determined (Canadian Mental Health Association, Division Office, 1997). The Provincial Mental Health Board's plans have

been challenged by both the Canadian Mental Health Association, Division Office, (1999) and the Provincial Health Council of Alberta (1998).

A small number of studies regarding consumers' preferences for housing and supports have been undertaken in the United States, but very few have occurred in Canada (Tanzman, 1993). As to consumers' experiences with housing and supports, the writer could find no studies specific to this area. The Canadian, Alberta and Calgary context is decidedly different from the United States and warrants this type of research being pursued here.

Purposes of the Research

The study has a number of interrelated purposes. The first of these relates to planning for mental health services and policy development. Studies of consumer experiences aim to provide valid and reliable knowledge for policy makers as they create new policy. From a national policy perspective, values of empowerment and consumer choice are now being considered. The results of the study could assist mental health policy makers in responding more effectively to the mental health consumer's needs.

Another purpose of the study is for service development and strengthening of service provision. A few agencies in Canada, namely some regional offices of the Canadian Mental Health Association, are beginning to offer Supported Housing programs as an alternative to traditional housing and support programs. What would be helpful would be for the service system to have a better understanding of consumer's experiences and perceptions related to housing and supports so that providers could reconsider, reevaluate, develop or enhance existing services.

A third reason for this study has to do with mental health funding and advocacy. Competition for funding is fierce. Solid information as to what consumers have experienced and how they view this experience could prove invaluable in a time when existing services of a more traditional nature are being called into question. In addition, in order to advocate effectively, with or on behalf of consumer groups, with people who often are not well informed about consumers needs (lay people, politicians or legislators), current and accurate information from a consumer perspective would be an important component of the process.

A secondary benefit of the study underlies all those noted above. This research represents for the first time in Alberta, consumers actively being solicited for their voice regarding housing and supports. Although a climate exists in the mental health reform process in Alberta that speaks to some consumer involvement, no systematic hearing of their voices has been undertaken. This kind of process begins to promote consumer credibility and encourages those in positions of power in the mental health system to rethink or to consider for the first time matters of consumer choice and empowerment. It is an important first step to self-determination of consumers and an enhancement of their worth and dignity. Finally, research on consumer experiences and preferences provides valuable information as to how relevant the existing mental health service system, including the policy branch, is to mental health consumers.

The next six chapters of this thesis represent an attempt to understand the information obtained from the mental health consumers interviewed for this study. In Chapter Two, an examination of the context of the study is provided. Following the definition of key terms, an historical perspective of mental health services and a theoretical

review regarding ways of understanding and intervening in mental health problems is outlined. Next, the literature related to housing and supports is also reviewed. The rationale of this research is put forward as are the research questions that are to be addressed in this study.

In Chapter Three, the research methodology used for this study is discussed. Chapters Four and Five present the findings of the research. Chapter Four represents the data related to consumers' experiences with housing and supports. Chapter Five consists of the respondents' preferences in the areas of housing and supports. In Chapter Six, there is a discussion of the research findings and their relationship to the existing research literature on housing and supports. In addition, a reconceptualization of housing and supports that this research has generated is proposed along with further research questions that should be pursued. Chapter Six also includes a section on the implications of the study results for mental health policy and programs, social work education and social work practice. This chapter concludes with recommendations for additional research in the area.

CHAPTER TWO

THE BACKGROUND AND LITERATURE REVIEW

This chapter provides the context for this research on the experiences and preferences of adult mental health consumers with housing and supports. The first section includes the North American statistics related to the incidence of mental disorders, a discussion of the changes that have occurred in the mental health system and some of the difficulties that are associated with these changes, and a focus on a definition of terms. An overview is given next, of the historical trends of institutionalization, deinstitutionalization, and the community mental health movement in order to understand how people with mental disorders have been treated. A theoretical review regarding our understanding of the etiology of mental disorders and the interventions that ensue from these theoretical perspectives follows, along with an examination of the literature related to housing and supports. The rationale for this study is provided along with the research questions.

Mental disorders constitute one of the most serious and perplexing problems in Western society today (Holmes, 1991). According to the Canadian Mental Health Association (1999a), mental illness strikes more Canadians each year than all other diseases combined. One in five Canadians will experience a major mental health problem in his/her lifetime (Canadian Mental Health Association, 1999b) and one in eight can expect to be hospitalized (Canadian Mental Health Association, 1999b). Nearly one half of the people in general hospital beds are there because of mental or emotional problems (Canadian Mental Health Association, 1999b).

Society's attempts to address the individual's mental health problems have gone through a variety of phases (Mu-jung P. Lin, 1995; Stein & Santos, 1998). During the last

two decades in Canada many people who would have traditionally been admitted to a mental hospital and would have had a lengthy admission have been affected by deinstitutionalization (Bachrach, 1983; Bassuk & Gerson, 1978; Canadian Mental Health Association, Division Office, 1997; Mechanic, 1999). People are being admitted to hospital for shorter periods of time and a number of people who historically would have lived out many of their years in a mental hospital have been discharged into the community. Additionally, fewer admissions have been occurring as mental hospitals tighten their admission requirements (Aviram, 1990; Mechanic). While it is difficult to estimate the numbers, more mental health consumers than ever before are living in the community.

Although this might seem like an ideal situation for mental health consumers, in reality they are experiencing difficulty. Present services for deinstitutionalized mental health consumers are not all that effective in addressing their needs for housing and social supports and our current system is not responding as well as it could (Canadian Mental Health Association, Division Office, 1997; Mechanic, 1999; Provincial Health Council of Alberta, 1998). In addition, the medical model, which has greatly impacted mental health services, has offered too narrow a framework to address the needs of people with mental health problems (Aviram, 1990; Mechanic) and it is often in direct opposition to those who view consumers' needs more broadly (Provincial Health Council of Alberta, 1998).

Moreover, criticism abounds as to the apparent ineffectiveness of various mental health programs (Canadian Mental Health Services, Division Office, 1997; Provincial Health Council of Alberta, 1998). Problems with the transitional nature of many residential services have been noted and the continuum concept of housing has recently come under attack (Carling, 1995; Mechanic, 1999; Ridgway & Zippel, 1990c). It has been suggested

that both create major difficulties for the mental health consumer (Carling, 1995; Mechanic). The crisis in housing for this population is all too apparent (Johnson, 1990; Mechanic, 1999; Torrey, 1988). Boyer (1987) mentions the near disappearance of affordable housing and the increasing difficulty of finding safe, affordable, decent and accessible housing (The Premier's Council on the Status of Persons With Disabilities, Action Plan, 1990; Mechanic, 1999). Public agencies have little knowledge of the unique needs of the psychiatrically disabled and public housing projects prefer more "normal" individuals (Aviram, 1990; Mechanic, 1999). There is also a lack of coordination between mental health services and public housing agencies (Aviram; Mechanic; Stein & Santos, 1998).

Homelessness and substandard housing are also issues for those with mental disorders. Ever increasing numbers of the homeless mentally ill are on our streets and are on the streets of most major cities in North America (Goering, Durbin, Trainor, Paduchak, 1990; Mechanic, 1999; Torrey, 1988). Studies are indicating that between one sixth to two-fifths of homeless individuals have a psychiatric background (Aviram, 1990; Ridgway & Zippel, 1990(c); Torrey, 1988) and many of the psychiatrically disabled are living in sub standard housing. Both the public and professionals alike have attributed this situation to the mental health system (Ridgway & Zippel, 1990(c)).

Across North America, a number of mental health consumers are living in poverty and are unemployed or underemployed (Carling, 1995; Edmonton Social Planning Council, 1995; Mechanic, 1999; Premier's Council on the Status of Persons with Disabilities, 1990; Torrey, 1988). Currently in the Province of Alberta, the income support program for adults

with severe and permanent handicaps who are unable to work is \$823.00 per month (Canadian Mental Health Association, 1999).

In the midst of these difficulties, the mental health service and the social welfare systems are debating which system has the responsibility to respond to the housing and support needs of people with psychiatric disabilities (Aviram, 1990; Mechanic, 1999; Ridgway & Zipple, 1990(c); Tanzman, Wilson & Yoe, 1992). To date, these systems are not responding in a coordinated and effective manner to address the issues.

The "revolving door syndrome" still occurs where mental health consumers are admitted to hospital, are subsequently discharged into the community, experience a recurrence of their mental health problems, are readmitted to hospital and then again are discharged (Mechanic, 1999; Stein & Santos, 1998). Hatfield's (1992) research indicates that most mental health consumers are being discharged to their parental home with parents acting as total caregivers (Ridgway & Zipple, 1990(a)). Parents feel overwhelmed by these responsibilities (Morrissey & Este, 1997) and they wish that their relatives could live elsewhere. Interestingly, the family member with the disability is indicating the same desire (Keck, 1990; Tanzman, Wilson & Yoe, 1992). A recent study in Calgary indicated that families involved with mental health consumers need information, education, services and supports (Morrissey & Este, 1997).

Some mental health consumers are living in group homes, ostensibly because this is the level of housing and service they require. Studies have shown, however, that this is not their preference (Fields, 1990; Keck, 1990; Tanzman, Wilson, & Yoe, 1992). Many residential programs are little more than boarding homes with a number of restrictions (Fields, 1990) and/or community institutionalization (Ridgway & Zipple, 1990a).

Furthermore, social stigma is still evident for the psychiatrically disabled. A number of researchers have indicated that stigma is a factor in community reintegration (George, 1995; Mansouri & Dowell, 1989; Stein & Santos, 1998).

It is evident then that there are serious difficulties for people with mental health problems. Efforts to deal with these have met with varying degrees of success and failure (Canadian Mental Health Association, Division Office, 1997; Provincial Health council of Alberta, 1998). The Provincial Mental Board in its housing report (1996) indicates that "accessible, affordable and safe" (p.1) housing is imperative for maximum functioning of those with severe and persistent mental illness. The Provincial Mental Health Council of Alberta (1998) suggests a focus on mental health reform, including a recognition of two perspectives: a) an emphasis on the integration of mental health consumers into the community and b) an integration of mental health services. Therefore, the problems related to housing and social supports warrant intensive and ongoing consideration for research, policy development and practice.

Definitions

When examining the mental health literature, it is apparent that a variety of terms are used to refer to people with mental health problems and to define their condition(s). This can and does result in confusion. Thus, some discussion and clarity is required.

Patients, ex-patients, clients, chronically mentally ill, mentally ill, seriously mentally ill, psychiatrically disabled and survivors are but some of the language employed. Each term represents underlying assumptions about the nature of mental health problems (e.g. that they are medical in origin) and some terms are stigmatizing (Carling, 1995) such as chronically mentally ill which connotes hopelessness. Often the term or label seems to

define the whole person. For example, we hear people say someone is "schizophrenic," implying that there are no other facets to that person's being.

Presently, the most widely used term to describe people with mental health problems across North America is that of consumer (Trainor, Pomeroy & Pape, 1993) and it is a term that many consumers prefer to use (Nelson, Ochocka, Griffin & Lord, 1998). It suggests that a person is more than their label, that there is hope and that the person can benefit from rehabilitation (Carling, 1995).

The conditions that the mental health system deals with are also referred to by a variety of terms. Again, what is apparent is that one's underlying assumptions about the nature of these conditions impact the language utilized. Psychiatric illness, mental illness, problems in daily living, and mental health problems are but some of the nomenclature used in the mental health field.

The History

From the earliest of times to the present, society has understood mental health problems in a variety of ways and intervened accordingly. However, western attitudes toward people with a label of mental illness have been almost uniformly negative (Carling, 1995). For example, in 1985, Peck was describing people with serious mental health problems as exemplifying the nature of evil in society. Blanch (1990) articulates clearly that the underlying assumptions society holds determines how people with a label are treated.

During the early twentieth century, mental health services were almost exclusively organized around mental hospitals (Johnson, 1990; Mechanic, 1999). Typically facilities were built in more remote or rural areas resulting in isolation and segregation of the person

with the mental health problem. A negative aspect of people being placed in institutions, away from their home community, was that the general public had little experience with the mentally ill and they believed that these people were being well cared for in the mental institution.

In actual fact, life in the mental hospital was one of deplorable conditions including overcrowding that was commonplace. The hospital was the place for not only the psychiatrically disabled but also those with epilepsy, mental retardation, alcoholism, and problems related to aging (Mechanic, 1999). Interventions were not particularly sophisticated or effective. This was the era of insulin coma therapy, electroconvulsive therapy, and psycho-surgery, namely the lobotomy (Simmons, 1990). Concerns were raised that psychiatrists were treating people as human guinea pigs, that some therapies were actually for social control reasons (the lobotomy), and that the person with the mental health problem was not allowed any control (Simmons).

During the postwar era not much changed as admissions continued to rise. Psychiatrists became alarmed by the number of people refused admission to the armed forces because of their mental state, by the number of individuals in the armed forces with mental health problems, and the number returning from the war with these difficulties (Mechanic, 1999). The term "battle fatigue" was coined and psychiatry began to treat situational stress with brief hospitalization. Thus we saw the first evidence of psychiatry moving away from the asylum and the chronic caseload (Johnson, 1990; Mechanic).

During the 1950's, conditions in mental hospitals were still wretched and people were having extensive admissions. Empirical evidence and scholarly writings were pointing at the mental hospital as being a noxious, countertherapeutic, inhuman, and

subhuman environment where elements of social control were evident to guard against deviance while at the same time the institution fostered deviance (Johnson, 1990).

Wing coined the term "institutionalism" at the beginning of the 1960's as he perceived the placid regimented lifestyle in the institution as leading to deficits in social and self-help skills (Ramon, 1991). Barton (1959) agreed and proposed that the structure of psychiatric hospitals induced a neurosis-like state for both patients and staff. Goffman's (1961) portrayal of institutional life was one of it being inhumane, where dignity, privacy, choice and control were removed in return for shelter and some forms of professional intervention. He suggested that it was the structural nature of these institutions which lead to the oppression of the people housed in these facilities (Goffman, 1961; Johnson, 1990; Ramon, 1991). After awhile patients became dependent and felt they could not function outside the hospital (Holmes, 1991).

While institutionalizing the mentally ill was the primary intervention at that time, a number of influences called into question this way of responding to the mentally ill and a reconsideration of this approach occurred. There was the recognition of the expense of long term hospital admissions (Holmes, 1991; Simmons, 1990), that the costs of hospitalization were of such consequence that they could not continue, and that maybe community treatment would be cheaper (Mechanic, 1999; Simmons) and more effective (Holmes; Mechanic). New treatments were being developed, as psychotropic medication was having profound effects on the mentally ill (Mechanic; Mu-jung P. Lin, 1995). Simmons suggests that their effects on patient behaviour made the mentally ill more acceptable to mainstream society. Psychiatry was moving away from only treating their patients in the mental hospital (Mechanic). There was the criticism of the hospital conditions (Nisbet, Clark &

Covert, 1991) and humanitarians believed that the negative aspects of hospitalization should be avoided (Holmes; Simmons).

Concurrently, the importance of political influences on mental health policy in North America could not be ignored. The President of the United States, John F. Kennedy in 1963, presented publicly the concept of community mental health services and suddenly deinstitutionalization and community psychiatry were being advocated for everywhere (Wright, 1967).

The concept of deinstitutionalization is used in a variety of ways. In its simplest form, it is a policy that has reduced significantly the number of people in mental hospitals. Johnson (1994) notes that it is based on the idea that the intervention and treatment of those with mental illness ideally would occur under those conditions that most closely resemble the environment that we live in. Surles (1994) mentions it as a concept that involves the shifting of responsibility for the mentally ill from a fixed location such as a mental hospital to a number of settings operated by both government and the non-government sectors. Aviram (1990) adds an additional dimension by referring to it as the trend and process of discharging large numbers of patients from mental hospitals into the community and the avoidance of and reduction in hospitalization of mentally ill people. Mechanic (1999) indicated that along with the difficulties associated with the lack of clarity regarding the meaning of the term deinstitutionalization is that the population discharged from mental hospitals is also a heterogeneous collection of varying patient cohorts.

While the impact of the developments in the United States during the 1960's did spill over into Canada, in western Canada specifically, the province of Saskatchewan was already in the forefront, leading the way for wide-spread changes in the provision of mental

health services. Certainly the concerns and issues related to serving the mentally in large mental hospitals in Canada mirrored those identified elsewhere. However, it was the responsiveness of Professor McKerracher, Director of Psychiatric Services for Saskatchewan, to a report from the World Health Organization in the early 1950's, that planted the seeds for the Saskatchewan Plan which, as it evolved, sparked an exciting and progressive era in the mental health field in Canada (Lawson, 1967).

The views contained in the Saskatchewan Plan (Lawson, 1967) offered a whole new way of approaching the provision of mental health services. The basic premises were that: (1) no person should be incarcerated in a mental hospital against his/her will, (2) the mentally ill should have the same standards of care, equally available, as those with physical illnesses and that psychiatric care should be integrated with medical and surgical care so that the whole person could be treated, (3) assessment and comprehensive care should be provided in the person's home community and/or home and the consumer should not have to go to a distant hospital solely because of the length or severity of his/her illness, (4) no government department should have control over clinical services including psychiatry so that there would be no greater political interference in psychiatry than any other branch of medicine, (5) the province should be broken into regions with regional facilities and services so that a patient would have the continuity of care and could not be abandoned if their particular problems were difficult to deal with and (6) the design of the regional psychiatric centre should provide for all types of treatment in a humane manner, taking into account the individuality of each person

The province was divided into eight regions and in 1963, regional community mental health clinics staffed by multi-disciplinary teams were established. Soon after in

1964 and 1965, regional psychiatric centres at both Yorkton and Prince Albert were approved.

While doubts had been cast upon the effectiveness of this model, subsequent evaluations pointed out some interesting findings. The most important finding was the success of the psychiatric unit in a general hospital and that it was not necessary to transfer patients to a provincial psychiatric facility (Lipscombe, 1970). In addition, fewer hospital beds were required than what had been initially thought (Lipscombe, 1972). The cost of serving a patient under this model was significantly reduced when compared to serving a patient in a provincial psychiatric hospital and the length of hospital stay was halved (Lipscombe, 1972). However, bed use and length of stay did not necessarily indicate a high quality of care (Lipscombe, 1972). Effective planning, organization and control was determined to be almost as important in the provision of services as accurate diagnosis and high standards of care (Lipscombe, 1972; Neufeldt, 1971). Psychiatrists consulting to the patient's general practitioner on psychiatric concerns was most effective and provided for continuity of care for the patient (Smith, 1965). Over 50% of the patients discharged from mental hospitals and referred to as chronic patients, remained in the community five years after discharge. 24% were still gainfully employed after four years and the community mental health clinics were able to provide for 80% of their care (Fakhruddin, Manjooran, Nair & Neufeldt, 1972). Former patients reported feeling both quite satisfied and reported having made great progress from the community system (Herjanic, Stewart & Hales, 1968).

Following on the heels of the Saskatchewan Plan, the Alberta government commissioned Dr. Blair to examine the Alberta mental health system. The report that ensued, entitled Mental Health in Alberta (1969) or the Blair Report as it was commonly

referred to, presented a comprehensive review of the Alberta mental health service system. The sweeping reforms contained in Blair's report provided the impetus for deinstitutionalization and a major overhaul of mental health services in the province, including the development of a new Mental Health Act in 1972.

Similar to Saskatchewan, across the province of Alberta, community mental health clinics developed, staffed by a variety of helping professionals including a consulting psychiatrist. There was an emphasis on serving those with mental health problems in their home communities and a recognition that there was more to treating the mentally ill than treatment based entirely on the medical model. The two large provincial psychiatric hospitals began to discharge patients in large numbers and community services emerged. Thus deinstitutionalization and the community mental health movement in Alberta was born.

Considerable debate exists as to the effectiveness of deinstitutionalization and the subsequent development of the community mental health movement. Some have argued that across North America there was no plan in place at all for the process of deinstitutionalization to unfold and that in actuality, patients who were once warehoused were instead dumped and abandoned in the community (Holmes, 1991; Johnson, 1990). Community mental health centers were ill equipped to deal with the chronic mental health population nor were services in the community comprehensive (Anthony & Liberman, 1994). Others suggest that deinstitutionalization never really occurred. Instead they indicate that the majority of the mentally ill remain in institutions, programs needed in the community are generally not developed, and patients were transinstitutionalized to nursing homes, boarding homes, and foster care settings (Carling, 1995; Johnson, 1994). Still

others note that the downsizing of mental hospitals has been considered progressive without much attention paid to what happens to the patients after this (Anthony & Liberman, 1994; Holmes, 1991).

Surles (1994) is clear that deinstitutionalization did take place and suggests that there is evidence to support his claim. He refers to the fact that many general hospitals now have inpatient psychiatric units and also provide psychiatric emergency services. He mentions the provision of assured income support programs for the psychiatrically disabled as an important policy addition. Surles also noted that the community support services concept was developed and that multitudes of community programs have sprung up.

For the most part, in Canada, financial supports for the consumer did not follow them from the hospital to the community (Trainor, Pomeroy & Pape, 1993). In the province of Alberta, seventy-five percent of government funds spent on mental health services are spent on hospital-based programs (Provincial Mental Board, 1995). While a more recent government document suggests additional funds are moving to the community mental health sector (Alberta Health, 1998), the amount and their impact on services are difficult to determine and have been negatively critiqued. The major criticism centres on the inadequacy of the financial resources available to address the consumers' community needs for services and supports (Canadian Mental Health Association, Division, 1998; Provincial Health Council of Alberta, 1998).

In the United States, sixty six to seventy percent of the mental health budget is spent on inpatient care (Aviram, 1990; Johnson, 1994). What is interesting are the discrepancies. Some states have altered their funding models to support community mental health services.

For example, Wisconsin spends twenty percent of their mental health budget for its mental institutions, while New York spends about eighty five percent (Aviram, 1990).

In order to understand the treatment of consumers in the community, the definitions of community and community mental health need to be explored. The term, community, in the mental health field has many different meanings and it is a critical term to clarify as we hear of community-based services. Often people are referring to a geographic location, outside a large mental institution. Others propose community to include a number of essential ingredients: (1) the people living in a certain place interacting with one another, (2) possessing a group identity, (3) sharing a common culture and values, and (4) all part of the fabric of a social system which implies commonality, connectedness and reciprocity (Connor, 1975; Taylor & Racino, 1991; Trainor, Pomeroy & Pape, 1993).

The concepts that policymakers and service providers hold of community are particularly relevant. Some community-based programs seem little more than a replay of programs that mental institutions offered. Many programs were not effective before and are not effective now, but since they are offered in a geographic location other than the institution, they are called a community program. However, they may not be responsive to community needs (Trainor, Pomeroy, Pape, 1993).

Langsley (1975) in his literature review of community health emphasized a set of criteria that still seem relevant today, and included:

- (1) commitment to a population, (2) use of all appropriate treatment methods, (3) continuity, (4) prevention, (5) consideration of all etiological factors, (6) use of multidisciplinary teams, (7) citizen participation, (8) avoidance of hospitalization, (9) linkage with the human service network, (10) use of mental health consultation,

(11) accountability, (12) education, and (13) focus on health rather than illness” (pp.37-41).

Others have conceptualized community mental health as a philosophy, program or concept (Holmes, 1991; Langsley, 1979; Mu-jung P. Lin, 1995).

In Canada in the late 1960's and 1970's, large numbers of patients were discharged from mental hospitals. Local psychiatric units in hospitals and community programs were gradually developed although they evolved in a piecemeal fashion as no uniform mental health policy existed (Canadian Mental Health Association, Division Office, 1997; Mechanic, 1999; Nelson, Walsh-Bowers & Hall, 1998b).

In the 1980's and 1990's, across North America, many more community programs came into existence and some would say an elaborate maze exists (Canadian Mental Health Association, Division Office, 1997; Mechanic, 1999; Provincial Health Council of Alberta, 1998; Surles, 1994). What is evident is that they vary tremendously from community to community.

While mental policy and services differ across North America, there is the growing concern about the effectiveness of mental health services in addressing consumers' needs. Simply discharging consumers into the community is now being recognized as insufficient to improve their condition (Aviram, 1990). Implementing community programs that merely duplicate hospital based programs is not the answer (Johnson, 1994; Trainor, Pomeroy & Papp, 1993). Government policies and initiatives that emphasize a comprehensive community mental health system while funding is retained with the mental hospitals are being viewed with cynicism (Canadian Mental Health Association, Division

Office, 1997; Carling, 1995). As Johnson (1994, p.226) adamantly emphasized, "All we've done so far is to let the patients out; now we need to do something for them."

Theoretical Underpinnings of the Literature

How one understands the etiology of mental health problems and the role of housing and supports in the mental health consumers' rehabilitation and recovery process, bears a direct relationship to the interventions and services offered. Although few (e.g., professionals, researchers) would argue for a single view in explaining mental health problems, the theoretical frameworks one subscribes to directly shape government policy, service delivery models, mental health programs and services offered. In addition, one's understanding of mental health problems is also related to what role one believes the mental health consumer and other key stakeholders should play in these areas.

Another confounding factor is the frequently reported lack of precision with which people are diagnosed or assessed (Brodsky & Faust, 1994; Ferrari, 1982; Mazque & Miller, 1994; Rose, Peabody, & Strategias, 1990; Stuart, 1973). In one study alone, 30% of the patients admitted to a New York City mental hospital were misdiagnosed (Lipton & Simon, 1985).

Various theories have been used to explain or help us put mental health problems in a particular context. Prevalent theories can be grouped into a number of categories such as biological, sociological, and psychological theories with biological theories having had the most impact in the mental health field.

Biological Theories

Biological theories have dominated the mental health field for many years and are presently enjoying a resurgence (Aviram, 1990; Carling, 1995). Two of the prevalent

biological theories relate to brain dysfunction and genetics. Brain dysfunction assumes that a malfunction of the brain is related to the development of mental health problems (Carling, 1995) while other research points to genetic factors playing a role in mental illness (Black, 1994). Naturally medical theories of mental illness have led to treatments based on the medical model, namely the use of psychotropic drugs, psychosurgery, electroconvulsive therapy (ECT) and genetic counselling.

Although some would conclude that the evidence is overwhelming that mental illness is a brain disease (Torrey, 1988), others argue that genetic factors are involved (Black, 1994; Littrell, 1994). Twin studies particularly point to genetic factor involvement in some mental illnesses (e.g., schizophrenia) (Austrian, 1995; Mechanic, 1999).

However, a number of criticisms have been leveled at these schools of thought and the research on brain disease or heredity related to mental illnesses does not account for all the cases of mental health problems (Austrian, 1995; Mechanic, 1999). Several authors (Aviram, 1990; Nelson, Walsh-Bowers & Hall, 1998b) suggest that it has been shown that many of the problems of the consumer are related to social factors such as poverty and/or the welfare system, inadequate housing, and unemployment rather than medical factors. Yet the medical model continues to locate mental problems within the individual with little support for addressing systemic factors. In regard to genetic factors, Littrell (1994) argues that although these aspects are related to mental illness, unwarranted inferences follow such as the disorder being fixed at the time of conception or that chemical intervention is the best approach. Consequently neither the individual nor the environment can be held accountable for the mental condition. A further criticism is that because the medical model concerns

itself with acute care problems it cannot deal with the chronic nature of some mental health problems (Aviram, 1990).

While evidence certainly points to biological changes that occur for those with mental disorders (e.g., the regulatory function of neuroreceptors breaks down in those people with depression), many other factors have also been identified. These factors are more in the psycho-social realm and result in a need for interventions that are not strictly only medical in nature. However, the power that the medical profession holds in our society, and in particular, psychiatrists in the mental health field, make this broadening of perspective difficult to enact.

Psychological Theories

While various psychological theories exist, for the purposes of this literature review, two have been identified and reviewed. These are theories related to development and social learning theory.

Developmental Theories

Developmental theories typically fall into two categories, those that relate to the individual (e.g., Erickson's and Sheehey's theories) and those that relate to families (e.g., McGoldrick's theory). Developmentalists look at the entire life cycle. These theorists articulate that both individuals and families go through predictable stages and that there are tasks or issues that must be addressed or resolved during these stages in order to successfully proceed to the next stage (Ward, 1998). Developmental theories are relevant to mental health consumers as many of them are thwarted in their attempts to developmentally proceed through life like others (e.g., have meaningful employment, enjoy intimate relationships or complete post-secondary education) and these difficulties adversely affect

them. The same can be said for their families when they end up having their adult children living with them when they, themselves, are entering their later years.

Ward (1998) raises a number of criticisms of developmental theories. Individuals and families do not necessarily fit with the lock-step concept of stages. The stages of family development seem to pertain, for the most part, to the nuclear family, while in reality many other forms of the family are present in our society. A third criticism is that developmentalists focus primarily on the individual or family with little regard for the impact of external systems.

Social Learning Theory

Social learning theory considers all behaviour, both adaptive and maladaptive, as learned. Mechanic (1999) suggests that the understanding scholars have of the learning process is that behaviour is learned through a process of reinforcement. Thus when we move into the mental health area, learning theory's ideas indicate that it is possible to use behaviour therapy to reinforce strong adaptive behaviour and weaken the reinforcement of maladaptive behaviour.

The contribution of social learning theory to the mental health area has been mixed. Mechanic (1999) indicates that behaviour therapy only impacts an individual's symptoms but does little to deal with the origins of mental health problems and that new symptoms often emerge. It is also difficult to be exact as to the stimuli that precedes behaviour and that the therapeutic work is long. However, Mechanic suggests there is much evidence that supports the effectiveness of behaviour therapy in addressing anxiety disorders and self-mutilation.

Sociological theories

A number of sociological theories have been posited that attempt to explain the etiology of mental health problems. Two system theories, that is, family systems and ecological theory, and labelling theory and social stress theory are articulated and examined.

Systems Theories

A systemic perspective considers individuals, not as functioning in isolation, but instead in interaction with a variety of systems. Ludwig von Bertalanffy articulated the general system's theory which originated from his work in the biological sciences (Turner, 1979). Family system's theory and ecological theory are two systemic views that are examined below.

Family System's Theory

Family system's theory grew out of general systems theory. It conceptualizes a family as a social system with all the properties of any system such as roles, rules, boundaries, structure and communication patterns (Goldenberg & Goldenberg, 2000). Family system's theory assumes that when an individual is part of a family system, a change in one person affects the rest of the members of the system. The focus of intervention then is on the family as the unit of change and the faulty interactions, structures and roles in the system (Goldenburg & Goldenberg, 2000; Payne, 1991; Ridgely, 1999; Ward, 1998).

For most people, the family is a major institution from which support is gained. This holds true for mental health consumers as well. What is also known is that in certain families the family dynamics are complex and stressful and this stress may contribute to

further difficulties for the individual with a mental disorder, including difficulties living in the family home (Goldenberg & Goldenberg, 2000).

The significance of this theory in the mental health field is that it underscores the necessity of working with the whole family as all are affected by the psychiatric disability of the family member. This focus has been largely ignored as families struggled to cope on their own (Hatfield, 1992; Morrissey & Este, 1997; Trainor, Pomeroy & Pape 1993). However, more programs and services that recognize the importance of the family in the work with the mental health consumer are beginning to emerge. An emphasis of programs on family education and practical ideas for living and dealing with a family member with a mental health problem are becoming evident as is the acknowledgement that all mental health consumers are not children. For example, programs aimed at helping children cope when their parent has a mental health problem are now in existence and are a focus for evaluation.

Various criticisms of family system's theory have been leveled. They range from the fact that it assumes that the family wants to stay together, that it overlooks the experience of the individual, that its basic premise is that all contribute to problems (which has a ring to it of blaming the victim), and that there is little consideration of social factors (Ward, 1998). Recent longitudinal studies suggest certain personality traits, patterns of behaving and social skills are developed in children before adolescence and these can increase vulnerability to various mental disorders in adulthood (Mechanic, 1999). Mechanic also notes, interestingly, that inadequate parenting is not a predictor of future mental health problems.

Ecological Theory

Another system's theory, ecological theory, assumes that people are constantly adapting in an interchange with many aspects of their environment and that they must be viewed in the context of the systems around them (Payne, 1991; Querault, 1996; Rothery, 1999; Turner, 1979; Ward, 1998). Ecological theory identifies major systems with which people interact, namely the micro, mezzo, and macro systems (Querault; Ward). Ecological theory's scope of concern is on more than viewing the origin of mental health problems originating within the individual. Instead the focus is on understanding a mental disorder in the context of an individual in interaction with a number of systems or different levels of a system (Hall, Nelson, & Fowler, 1987; Payne, 1991; Rothery, 1999; Turner, 1979; Ward, 1998).

Ecological theory provides a conceptualization that helps for understanding housing and supports for mental health consumers in systemic way. Using community housing for consumers as an example, this system's perspective would consider a number of dimensions of community housing in relation to the consumer and their functioning. The types of housing available and the quality of that housing (e.g., a micro level focus), how consumers are received in the community in which they live (e.g., a mezzo level focus), the nature of both housing policies and programs and their impact on the consumer (e.g., a macro level focus), and how the housing systems and mental health service systems work together (e.g., a macro level focus) are all considered when working with the consumer from this framework. The consumer, their mental health difficulties and their interactions with these systems would all be viewed as important factors in a person's functioning.

Ecological theory, then, takes into account a broader system's focus when understanding human problems and intervening. Change includes much more than a focus on the individual and change needs to take place within various systems and at a societal level. Thus ecological theory's real strength is in its explanation of how an individual and various systems in society interact and contribute both to individual's problems and solutions to the problems (Ward, 1998). However, it pays little attention to facets of the individual that may contribute to their mental health problems.

Labeling Theory

When discussing theoretical frameworks that help explain mental health problems, one would be remiss if labeling theory was not mentioned. Laing and Szasz are credited with developing this theory which basically states that mental health problems reside in their definition; that is, they are socially constructed and, thus, are a social phenomena rather than an individual illness (Johnson, 1990; Mechanic, 1999; Turner, 1979). Their premise is that social control follows from the social definition and social control responses define, create and sustain social problems. According to Johnson (1990), "Diagnoses are too often little more than a pejorative label applied to persons whose behaviour offends or annoys others" (p. 58). Torrey, (1974) adds that calling consumers sick only shows our own arrogance in implying that the rest of us are well.

While Szasz and others do not deny the existence of mental disorders, they believe they are not diseases but more a reflection of problems in daily living or deviations in thinking and behaving that are judged negatively and then labeled (Johnson, 1990; Mechanic, 1999). They suggest that once a label "sticks" that stigmatization begins and a self-fulfilling prophecy takes place.

Their position is controversial and opposition critics conclude that we are still left with real people with real problems that need to be dealt with (Johnson, 1990). Labeling theory's usefulness in clarifying etiological questions has been called into question. However, labeling theory has been particularly helpful in recognizing that how those with mental disorders are viewed by professionals, caregivers or the rest of society influences their place in the community and their rehabilitation and recovery process (Mechanic, 1999).

Social-Stress Theory

A number of social scientists see mental disorders resulting from the stress associated with severe problems of daily living. These include factors such as extensive emotional or economic deprivation. The behaviour manifested reflects the person's ability to cope with an often difficult and hopeless situation (Johnson, 1990). Brenner (Johnson, 1990) linked the condition to circumstances beyond the medical model by his observation that "the prevalence of treated and untreated psychopathology is inversely related to socioeconomic level" (p. 61). He also found that hospitalization in mental hospitals increased during times of economic hardship (Mechanic, 1999). Brenner's ideas were that severe economic hardship brings about marked personality and social disorganization for people. They are then labeled, and understanding and supportive measures to provide reintegration into society does not occur (Johnson, 1990).

The results of Hollingshead's famous 1958 study, Social Class and Mental Illness, are aligned with Brenner's points. Hollingshead found that a distinct inverse relationship did exist between social class and mental illness; with the lowest class almost invariably

contributing many more patients than its proportion of the population warranted (Johnson, 1990; Mechanic, 1999).

Other research on the relationship between stressful life events and psychiatric conditions suggests there is some connection (Austrian, 1995; Mechanic, 1999). However, it must be recognized that our understanding of the interaction of life events in relation to other factors in predicting the development of psychiatric conditions is still in its early stages. Nevertheless, efforts to assist and support people during stressful life change events, the development of preventative programs and programs aimed at aiding individuals in enhancing their coping skills are both in existence and have shown some success.

In sum, scholars have contributed the idea that mental illness may be a function of phenomena entirely beyond anyone's individual control and certainly beyond the limits of the individually oriented medically model (Johnson, 1990). Recognizing stressful life events as a factor in the development of a mental disorder and assisting people in their ability to cope effectively is a perspective that important implications for our mental health service system.

Rehabilitation Theory (Psychiatric Rehabilitation)

Psychiatric rehabilitation is strongly emerging as an important way of working with people with mental health problems and it is increasingly popular (Rutman, 1994). While not always specifically addressed in the literature as the rehabilitation theory, psychiatric rehabilitation seeks to view individuals with disabilities as people who want to increase their capacities and functioning capabilities (Carling, 1995; Payne, 1991). The goal of psychiatric rehabilitation “is to restore each person’s ability for independent living,

socialization and effective life management” (Hughes, Woods, Brown & Spaniol, 1994, p.1).

While the term is used in varying ways and is thus somewhat imprecise, rehabilitation theory or the psychiatric rehabilitation model as it is sometimes referred to, does not presume a specific explanation for mental health problems (Carling, 1992; Rutman, 1994). Rather, as several authors (Carling, 1995; Rutman, 1994) indicate, psychiatric rehabilitation considers the “systematic utilization of a combination of specific modalities to assist in the community rehabilitation of persons with psychiatric disabilities” (Rutman, p.4), within the framework of a disability right’s perspective. As Anthony and Liberman (1994) suggest, psychiatric rehabilitation comprises interventions aimed at developing consumers’ skills while providing environmental supports to assist consumers in fulfilling the various role demands of living in our society.

Several principles or core qualities characterize psychiatric rehabilitation (Rutman, 1994). Participants are strongly encouraged to participate fully in normalized roles and relationships. When working with the psychiatrically disabled, the practical, realistic adjustment needs related to all aspects of community living are paramount. Social learning and behavioural change is facilitated through experiential activities. Finally role, authority and status differences between mental health consumers and professionals are minimized.

The rehabilitation theory incorporates the concepts of advocacy and consumer empowerment. Advocacy has been practiced at the level of individual advocacy where services and benefits for clients were pushed for and second, at the level of systems advocacy (cause advocacy) to promote change for the benefit of the larger group (Payne, 1991). In the mental health field we have seen consumers demonstrate their capacity to

manage their own lives and to achieve their civil rights both within and outside the mental institution, partially by gaining more power to control their lives. This is often referred to as consumer empowerment (Nelson, Ochocka, Griffin & Lord, 1998; Payne, 1991).

Essentially, rehabilitation theory seeks to concentrate on the integration of individuals with mental health problems into society. It does this by enhancing consumers' functioning using a holistic perspective, and by providing opportunities for consumers to take on normalized roles and relationships (Rutman, 1994).

Research regarding the effectiveness of the psychiatric rehabilitation model is being undertaken, with results of the research beginning to emerge (Test, 2000). What it is suggesting is that psychiatric rehabilitation is positively impacting people with mental health problems by assisting them in carrying out life's role demands and is also a factor in reducing hospitalization for this population (Anthony & Liberman, 1994, Carling, 1995). However, further research related to utilizing this approach when working with the mental health population is required (Test).

Conclusions on Theory

A large number of theories are posited as to the etiology of mental health disorders, associated factors and appropriate interventions needed to address people's mental health difficulties. The research on the etiology of mental disorders and the effectiveness of various interventions is vast and often contradictory. The theoretical perspectives and the assumptions contained in a theory impact significantly how an individual with a mental health problem is assessed and ultimately intervened with. At the same time, the number of mental disorders identified are numerous, as evidenced by the listings in the D.S.M.IV

(1994), and these are changing as the manual is updated and disorders are added or dropped from the manual.

Ultimately few people would argue for a unitary explanation of mental health problems or their solutions. What is so important to recognize though, is that one's understanding of mental disorders should be and usually is directly related to the type of intervention provided including the formation of public policy (Mechanic, 1999). This recognition is critical when we begin to contemplate how best to respond to the needs of mental health consumers.

At this point in time, theoretical perspectives help us in understanding the etiological factors involved in the state of our mental health, what elements contribute to the course of mental health problems and how we might best intervene. No one explanation or singular type of intervention is going to be the solution. Factors that are physiological, chemical, genetic, social, environmental, cultural, or familial all must be considered when working with the mentally disordered.

The medical model is the most prevalent perspective used by doctors and those working in health care settings and physicians still have the most influence over treatment in the mental health system. However, it is in no way the total answer as evidenced by the problems noted earlier. While the mental health system is still heavily weighted on the side of the medical model, consideration of other models, which may work in tandem, is essential.

The conceptual framework that seems to have taken root and is being utilized most commonly in the field today by other mental health professionals is that of psychiatric rehabilitation (Carling, 1995; Jacobsen, Burchard & Carling, 1992). Although it does not

provide a definitive understanding and clarification of mental health problems this framework "proposes a functional view of individuals, ... with independent living as its goal, and a need for rights protection and social change" (Carling, 1995, p.72). In conjunction with psychiatric rehabilitation, the view that physical and social arrangements and other life factors and events also impact an individual's mental health is prevalent. Both mental health consumers and professionals alike are advocating for these factors to be considered as a relevant dimensions of consumers' recovery and community integration.

Review of the Literature Regarding Housing and Supports

Reviewing the literature regarding housing and supports for mental health consumers provides a context for this study. This section examines a number of articles and studies that contribute to an understanding of these areas.

A bewildering array of terms is used regarding housing. Housing, supported housing, residential treatment, housing environments, a home and normal housing are examples of terms utilized. Some authors are very specific and define housing in terms of the type of housing (Linhorst, 1991), while others equate housing in terms of whom one lives with and the kinds of support required (Goering et al., 1992). Baker and Douglas (1990) focus on the quality and appropriateness of the housing environment. Hogan and Carling (1992) introduce a new concept to the literature by exploring normal housing where consumers utilize integrated, regular, generic housing, and where their preferences and choices are maximized. The consideration of normal housing for consumers seems to be an emerging direction (Carling, 1995; Taylor & Racino, 1991).

The word "supports" is also referred to in a variety of ways and takes on different meanings. Social supports, community supports, and rehabilitation are examples of a few

ways in which this term is referred to. Stroul (1989; 1994) states that the community support system is a concept that encompasses the whole assortment of services, supports and opportunities required by people in order for them to function in the community. She identifies client identification and outreach, mental health treatment, crisis response, health and dental care, housing, income support and entitlements, peer support, family and community support, rehabilitation services and protection and advocacy (1994).

Wilson (1989) says that while there is an inclination to focus on services when discussing the community support concept, guiding principles, ownership by key constituencies who will be affected and strong consumer and family involvement are necessary. Taylor and Racino (1991) discuss supports as what is needed, both formally and informally, to live in a home and participate in the community.

Rimmerman, Finn, Schnee and Klein (1992) discuss intensive care in an attempt to rehabilitate individuals and move them to higher levels of functioning. House (1981) views social support as related to financial assistance, emotional support, feedback and information. Fields (1990) offers yet another way to examine housing and social supports by clearly stating that "residential treatment programs" are not housing services but are treatment services offered in a residential setting. Other authors (Carling, 1995; Ridgway & Zipple, 1990b) use the term supported housing as an approach which underscores normal housing, consumer preferences and authority, and flexible supports including self-help.

Thus the conceptualization of the concepts of housing and social supports is muddled and varies among authors and researchers. Definitions tend to be inferred from how the writers have defined their terms or operationalized them, and in the worst cases the authors assume that all understand the terms that they use.

Community Housing in the Context of Community Supports

If mental health consumers are to function well in the community, appropriate housing is critical. However, consumer housing needs do not exist in isolation of other community services and supports that may be required. As Moos (1974; 1976) recognized, human behaviour is influenced by situational and environmental forces to a much greater degree than is commonly recognized. An examination that focuses on understanding where housing fits into the community care system follows.

With the emergence of the psychiatric rehabilitation movement, there was a recognition that mental health consumers are beset with a range of needs, needs that must be addressed to assist in an individual's recovery. Many of these needs point to the necessity of service providers to expand their thinking and consider that to address mental health problems effectively, a focus on housing, finances, employment, education, leisure, coping skills, personal autonomy, social needs, and consumers' rights is paramount (Rutman, 1994; Torrey, Mead & Ross, 1998).

Stroul's (1989; 1994) research concentrated on persons with long term mental illness and identified a range of support services that act as the foundation for her community support systems (CSS) concept. She listed ten service components, which should be included within a CSS array of services, ranging from client identification and outreach to crisis response services, housing and various supports. Stroul stated that CSS is both a network of services and a philosophy that embraces "the notion that services should maintain the dignity and respect of the individual needs of each person", where "community is the best place for providing long-term care" (p.11). She concludes that CSS components must be organized into an integrated, coherent system.

Wilson's (1989) article describes the implementation of the community support system (CSS) concept, in the state of Vermont. Before implementing CSS, Wilson emphasizes certain foundational elements that must be in place. She underscores the need to articulate guiding principles and values, to create a strong coalition of support and ownership among all key constituent groups affected, solid involvement by the consumer and family, and sound project management. Once these building blocks are established, there needs to be an emphasis on the comprehensive quality of the CSS.

Knisley and Fleming (1993) also described the implementation of supported housing in the state of Ohio. They noted that both the state and county worked together in formulating and following comprehensive housing development plans and they identify that it is essential for state level leadership and expertise. They discussed the importance of both state commitment in financing and of the need for creative financing. They also emphasized the necessity for involvement of consumers and their families.

Although Trainor, et al. (1993) envision consumers living in the community, they take a slightly different position than Stroul (1989; 1994) with the CSS concept. They suggest moving beyond mental health policy based on a traditional service paradigm, in favour of a Community Resource Base (CRB) concept with the consumer at the centre of the model.

CRB encompasses three main aspects: (1) it is solidly person centred, (2) it includes four sectors, mental health services, family and friends, consumers groups and organizations and generic community services and groups, (3) it is based on the elements of citizenship. Thus, to establish a connection with the community and enhance their

citizenship, these individuals require appropriate housing, education, meaningful employment and adequate income (Trainor, et al. 1993).

The proposed "New Framework", although recognizing the value of the mental health system, advocates an increased role for family, friends, consumer and community groups, and self-help. Both the CSS and Framework for Support challenge the traditional approaches to policy development and the provision of services that have haunted us in the past, providing models that are much more holistic and comprehensive. Appropriate and adequate housing is considered crucial to each. A broad application of either of these visions can only strengthen community based, supported housing.

Research Related To Housing in the Mental Health Field

Research regarding housing is grouped into three major areas: (1) studies related to changes in outcome for the consumer such as reduced symptomatology, emotional well-being or an improved quality of life, (2) studies related to the housing setting and services provided and (3) studies related to establishing supported housing.

Studies Regarding Consumer Outcomes

Baker and Douglas (1990) researched the relationships between the quality and appropriateness of housing environments and community adjustment of previously hospitalized individuals who were severely mentally ill. The results of this study indicated that client needs for community support services were significantly related to the three measures of residential condition. Those living in the worst residential environments had the greatest number of unmet service needs and a decrease in quality of life. Poor housing had a significant relationship to poor community adjustment outcomes. Clients who were living in adequate housing showed significant improvement in overall functioning. Clients

moving from appropriate to inappropriate housing showed significant deterioration in overall functioning.

Rimmerman, Finn, Schnee, and Klein (1992) sampled clients suffering from severe mental illness. They were interested in discovering whether psychosocial rehabilitation services prevented rehospitalization and allowed for longer stays in the community, and if the "patients" who received psychosocial rehabilitation had a more lasting adjustment to community living. In addition, they were interested in examining whether people receiving rehabilitation services benefited from the services. Findings indicated low hospitalization rates, in fact, much lower than those reported in previous studies (Rimmerman et al., 1992). The provision of psychosocial rehabilitation services was associated with progress in outcome measures such as symptomatology, several therapeutic goals, ADL skills and social integration activities. The study provided support for using a number of types of therapy in combination.

McCarthy and Nelson (1991) studied hospital recidivism, instrumental role functioning, personal empowerment of former psychiatric patients, social support and decision making in residential care settings. After five months of supportive housing, residents noted improvements in personal empowerment and instrumental role involvement with dramatic reductions in hospitalization days at one year in the program. Staff control was inversely correlated with the residents' satisfaction with their privacy and personal empowerment, shared control with satisfaction with the facility and resident control was inversely related to satisfaction with how decisions were made in the facility and directly related to personal empowerment.

Nelson, Wiltshire, Hall, Peirson and Walsh-Bowers (1995) in related research examined psychiatric consumer/survivors' quality of life and found partial support for indicators of personal empowerment, social support, housing and community integration to be related to consumer/survivors' perceptions of their subjective quality of life.

George (1995) investigated whether people with chronic mental illness residing in various kinds of community housing experienced differences in their quality of life. He found that quality of life for a consumer was influenced by multiple factors, one of which was housing type or program. The influence of the housing program on quality of life diminishes as support and supervision are reduced and the community influences become more significant. A particularly important finding was that the quality of life scores for those living independently, with program support and supervision, failed to yield a quality of life that compared favourably with other housing types.

Srebnik, Livingston, Gordon and King (1995) assessed a major tenet of supported housing, consumer choice in housing selection, and the relationship of choice to community success. Greater choice was positively correlated to both happiness and life satisfaction ratings and less influence by others was also positively related to happiness ratings. Most consumers possessed only one housing option and believed that choosing this option was mainly influenced by others, particularly mental health professionals.

Witheridge's (1990) article examined the contribution of assertive community treatment to supported housing by illustrating the Thresholds Bridge Program in Chicago. Eleven program features were identified. These ranged from an expressed aim of preventing hospitalization or homelessness to a definite case management approach, in vivo locus of intervention, assertive advocacy on behalf of the consumer by both social services

and the mental health service system and a commitment to work with consumers as long as required. Threshold Bridge members had significantly fewer hospital admissions, shorter hospital stays and were more stable in the community. While most consumers in this group did not live in their own residences, for many it was due to prohibitive cost or an inability to manage the details of apartment life.

Goering, Durbin, Foster, Boyles, Babiak and Lancee (1992) sampled residents living in supportive housing in Toronto to examine their social support networks. The authors found that social support networks have direct and stress-buffering effects on health and well-being. In the psychiatrically disabled, greater network impairment is associated with increased symptomatology and prolonged illness. Their findings suggest that living in supportive housing has a positive effect on the social networks of residents but that staff and co-residents appear to partially replace rather than add to the network of family and friends. Of concern are the fewer number of friends in the resident's network and the possible consequences of this reduction.

Nelson, Hall and Walsh-Bower's (1999) recent Canadian research examined the housing qualities, social support, personal empowerment, and emotional well-being of a sample of mental health consumers related to the various types of housing that consumers were living in. They found that those living in both group homes and supportive apartments had more control over their lives, lived with fewer people, were more likely to have their own rooms, and indicated higher levels of personal empowerment. This was when compared to those living in board-and-care-homes. However, residents of board-and-care homes reported higher levels of emotional wellbeing than those living in the other two types of housing. The measures of housing and social support were predictors of

consumers' measures of personal empowerment and emotional wellbeing, beyond the type of housing and various demographics.

Studies Regarding the Housing Setting and Service Provision

Linhorst (1991) reviewed literature on the use of single room housing (SRO) as a residential alternative for persons with a chronic mental illness. His findings propose that SROs offer the resident independence as well as the opportunity to socialize. They can be utilized long-term, as opposed to transitional housing, and he argues that they are cost effective.

Fields (1990) examined the relationship between residential treatment and supported housing in a community system of services. His conclusions suggest that residential treatment and supported housing are not competing alternatives, nor does supported housing replace the need for residential treatment. Rather, the challenge is collaboration between the proponents of supported housing and residential treatment, emphasizing the need for a common philosophy.

Hatfield (1992) took a different approach by examining family members' views about preferred living arrangements for relatives with mental illness. In a prior study by Hatfield (1990), only three percent felt that the family home was appropriate. In the subsequent study, Hatfield (1992) tried to determine parents' perceptions of the barriers that prevent the separation of people with mental illnesses from their families. Interestingly, sixty-two percent of the parents were primary caregivers (Hatfield, 1992). Hatfield's findings indicated that the availability and quality of housing bears a direct relationship to the ability of mental health clients to separate from the family home. Client characteristics were also factors (e.g., functioning is too low; tends to be volatile).

Mental health consumers' preferences regarding housing and other supports have been explored by numerous researchers (Davidson, Hoge, Godleski, Rakfeldt & Griffith, 1996; Keck, 1990; Livingston, Srebnik, King & Gordon, 1992; Tanzman, Wilson & Yoe, 1992; Yeich, Mowbray, Bybee & Cohen, 1994). Consistent was consumers' preferences for living in their own home and wanting to live alone. Consumers wanted services such as help in acquiring housing. When this was provided, consumers were still in the same housing after 21 months and case managers reported consumers were satisfied with their quality of life (Keck, 1990). Consumers also wanted help in dealing with emotional upsets, financial matters and assistance in making friends. Poverty was a serious barrier to finding normal housing.

Hammaker (1996) took a slightly different approach by conducting a survey to examine consumers' housing and support needs from multiple perspectives, namely the consumers, families, practitioners and local administrators. While his results showed varied views depending on who was being surveyed, he also found that there were substantial shared views in the stakeholders' perspectives of housing and support needs. Medication information, housing choice and type, roommate choice, consumer rights and medication were the shared views of needs with the highest ranking (Hammaker).

Massey and Wu (1993) examined seven characteristics of a desirable living situation and then compared them with the perceptions of case managers and consumers. As in other research, consumers were most concerned with safety, comfort and privacy in independent housing. No significant differences were found between case managers and consumers on these factors. Consumers identified independence and personal choice,

convenient location and proximity of mental health services as significantly more important than did case managers.

Nelson, Hall and Walsh-Bowers (1998b) looked at the relationship between housing characteristics, emotional well-being and the personal empowerment of psychiatric consumer/survivors. They found that the number of living companions, housing concerns and having a private room all significantly predicted different dimensions of community adaptation.

A number of researchers (Nelson, Hall & Walsh-Bowers, 1997; Nelson, Hall & Walsh-Bowers, 1995; Nelson, Walsh-Bowers, Hall & Wiltshire, 1994; Nelson, Wiltshire, Hall, Peirson & Walsh-Bowers, 1995) examined the processes and outcomes of supportive housing for psychiatric consumer/survivors. In terms of the process research, the residents of supportive apartments and group homes were more likely to have their own room, to spend less of their income on rent and to have more control over decision-making than people living in board and care homes. Residents of group homes and board and care homes had more staff support, more emotional and problem-solving support and less emotional abuse than residents of supported apartments. The outcome analyses indicated that residents in all three housing types of housing increased their involvement in instrumental roles such as work and education and those in group homes and supportive apartments showed increases in independent functioning. Qualitative data indicated more changes for group home and supportive apartment residents in terms of personal growth, improved health and emotional well-being and increased community involvement as compared to board and care residents.

Hadley, McGurrin and Fye (1993) examined community residential services and community tenure for a group of people discharged from the Pennsylvania state mental hospital. Their findings indicated that partial hospitalization as an aftercare service had the largest impact on community tenure, likely because it involves more service hours and supports for consumers. Those living in personal care boarding homes had the longest average community tenure, more than those living in community residential rehabilitation groups.

Linney, Arns, Chinman and Frank (1995) explored environmental characteristics of an ideal living situation by comparing the perspectives of community care operators and mental health consumers. Both groups agreed on the importance of basic health and safety. Consumers viewed community accessibility, availability of health services and social and recreational activities as more important, as were privacy, autonomy and independence.

Diamond (1993) focused on the role of the psychiatrist in supported housing, a role that has not been clearly defined. He recognized their function of prescribing medications, attending to the consumer's medical needs and arranging for hospitalization when required. However, he mentions this with the proviso that the psychiatrist must support the consumer's goals, understand the fundamental values of supported housing, be able to tolerate role ambiguity and acknowledge the importance of the rehabilitative component for consumer's mental health.

Gill, Pratt, and Librera (1998) examined consumers' evaluations of service provision by looking at whether it mattered whether the tool utilized was administered by staff or consumers. What they believed at the onset was that consumers seemed to consistently rate service provision in a positive way, regardless of the quality of the service.

They discovered that while consumer administered questionnaires did not uniformly result in lower scores on quality of service provision, there were differences depending on who administered the rating tool, although these effects varied from program to program.

Studies Regarding Establishing Supported Housing

Hogan and Carling (1992) identify a developing consensus about the serious problems facing people with psychiatric disabilities regarding decent housing and how best to provide housing and support. They state that there is a growing recognition that people with mental health problems need homes not housing.

In the process, they have developed criteria for choosing normal housing. These include: (1) emphasizing common issues for selecting accommodation such as cost, affordability, physical condition etc., (2) following criteria for community integration, and (3) considering special features of housing applicable to the psychiatrically disabled (Hogan & Carling, 1992).

Carling's (1993) extensive review on housing and supports indicated consumers and their families were favourable to the concept of supported housing. They identified the need for innovative financing strategies, meaningful input of consumers in formulating housing and support goals, that support to consumers should be broad and flexible and that consumer choice is essential.

Cohen and Somers (1990) presented a macro-level analysis of the organizational, political and administrative changes that occurred in the Robert Wood's National demonstration project. They indicated that essential ingredients for a project of this type were: (1) the establishment of new housing development corporations, (2) training of

mental health agency staff members in the housing development process, (3) integration of housing and support services under the framework of a central mental health authority.

Newman and Ridgely (1994) examined and assessed the housing components of the Robert Wood's demonstration project, four years after its inception. Tremendous variation in the nine site's approach to housing was evident, which suggests that there is not a single model for developing and delivering housing to the psychiatrically disabled. There was consensus that the relationship between housing and service supports is essential. Fundamental observations were that adequate resources for ensuring services must be in place, with an appropriate process for coordinating housing and support services. Finally, the authors suggest that the development of an appropriate assessment instrument for tenant applications that would evaluate an individual's ability to live independently is imperative.

Carling (1990) indicated that the characteristics of the community, not the residents, are the most important predictors of consumers' involvement in community life. Aubry, Tefft and Currie (1995) investigated public attitudes and behavioral expectations regarding tenants of community mental health residences who are neighbours. Mildly disabled people were received more favourably by neighbours than severely disabled people. This finding suggests that people receive more equitable treatment if they only deviate a little from the norm. However, it is cause for concern, given that more severely disabled people are now living in communities. Ultimately though, respondents indicated a high level of receptiveness to having mental health consumers as neighbours.

Lord, Ochocka, Czarny, and MacGillivray (1998) undertook and documented a case study of change within a mental health organization, namely the Waterloo Regional Homes for Mental Health Inc. in Ontario. The change effort occurred because of tremendous

growth within the organization at a time when there was significant shifts in thinking in the mental health community towards a paradigm of community integration and empowerment. Three major themes emerged from witnessing and analyzing this organization's change process. The authors identified changing service delivery systems towards more individualized support, broadening the ownership of the change movement through stakeholder involvement and beginning to shift power and control through consumer participation (Lord, Ochocka, Czarny & MacGillivray).

Synthesis of Findings

Livingston, Srebnik, King and Gordon (1992) begin by identifying who is served by supported housing. The relationship between the quality, type, appropriateness and processes involved in housing and how consumers' function is starting to be documented (Baker and Douglas, 1990; George, 1995; McCarthy & Nelson, 1991; Nelson et al. 1999; Nelson et al. 1998; Nelson et al. 1997; Nelson et al. 1995; Nelson et al. 1994; Nelson et al. 1995). Consumer preference surveys are clearly indicating that consumers want their own housing, want normal housing, and want to live on their own and that responding to their preferences is equated with residential success (Carling, 1993; Hatfield, 1990; Keck, 1990; Tanzman et al., 1992; Tanzman, 1993; Yeich, Mowbray, Bybee & Cohen, 1994). The consumers' families also favour this approach (Carling, 1993; Hatfield, 1993). Goering, Durbin, Foster, Boyles, Babiak and Lancee (1992) found that supportive housing has positive effects on the social networks of consumers, but staff and co-residents appear to replace family and friends.

These findings fit nicely with what contemporary authors are proposing in terms of normal housing (Hogan & Carling, 1992; Marsh, Koeske, Schmidt, Martz & Redpath,

1997; Trainor et al. 1993). Given the lack of agreement among other stakeholders such as professionals and community care home operators, the need for both increased communication amongst groups and for additional research linking environmental conditions to consumer outcomes (Linney, Chinman & Frank, 1995; Massey & Wu, 1993) is indicated.

Lindhorst's (1991) article asks us to consider single room occupancy as a residential alternative for persons with a chronic mental illness. However, Tanzman, Wilson and Yoe, (1992) found single-room occupancy held the least appeal for consumers as compared with any other living situation, including the state hospital or homelessness.

Other research points to the importance of appropriate and adequate supports for consumers, that consumers with lower social skills need more support, and this support bears some relationship to lower hospitalization rates, increased community tenure, and if social skills are addressed, a more positive acceptance by neighbours (Hadley, McGurrin & Fye, 1993; Aubry, Tefft & Currie, 1995; Rimmerman, Finn, Schnee & Klein, 1992). To some extent this correlates with the community support services framework and the Canadian Mental Health Association's community process paradigm in terms of what is needed for consumer's community success (Stroul, 1989; Trainor et al. 1993; Wilson, 1989).

Fields' (1990) writings focus on residential treatment and how it works in tandem with supportive housing for the benefit of the client. However Tanzman, Wilson and Yoe's (1992) study on consumer preferences in terms of housing and supports found that the mental health facility, temporary housing, and community care homes were least desired by consumers. Hogan and Carling's (1992) article identifies the problems with the housing

continuum and the transitional nature of some housing programs, indicating that a move to "normal" housing is desirable. While Fields (1990) would deny that residential treatment connotes housing, the lack of clarity around terminology and some opposition to residential treatment as a future direction by both consumers and researchers calls his position into question.

The findings of Srebnik, Livingston, Gordon and King (1995) challenge mental health service providers to actually expand opportunities available to consumers for making their own housing choices. They suggest that policy changes to adequately meet the financial realities of community living are in order, as is meaningful consumer involvement in the mental health system.

Cohen and Somers' (1990) position on supported housing is contingent on the ability of key administrative stakeholders to lead agencies towards a supported housing model, as well as a willingness among traditional housing and real estate finance agencies to work with mental health authorities to address the needs of the mental health consumer. Researchers (Carling, 1993; Diamond, 1993; Knisley & Fleming, 1993; Stroul, 1989; Tanzman, 1993; Trainor, Pomeroy & Pape, 1993; Wilson, 1989) believe there must be a collaborative effort between government, mental health providers and consumers to develop comprehensive approaches to housing.

Conclusion of the Literature Review

From reviewing the literature, it is heartening to see a supported housing approach emerge for mental health consumers. However, few studies on supported housing currently exist. New directions are being considered and, at the same time, the consumer is starting

to have a voice in the dialogue about social policy and development of service delivery models.

Recent emphasis centres on enabling consumers to live in normal housing with the required social supports provided in their homes and communities. Further research to provide evidence that this is a viable and effective approach for enhancing the social functioning and quality of life for mental health consumers, focusing on the nature and scope of fundamental supports is required.

However while the supported housing model seems to hold promise, the mental health policy makers and service providers need to hear from the mental health consumer. The starting point seems to be for consumers to, first and foremost, identify their perceptions of their housing environments and preferences for housing and supports for the future. Little research exists on this in Canada, and a recent study in Calgary undertaken by George (1995) supports the need for and the importance of this type of investigation occurring.

Rationale for the Study

With the acknowledgement that two areas of need for mental health consumers are appropriate housing and supports, policy makers and service providers are considering how best to meet these needs. Frequently a variety of key informants, namely consumers' families, professionals, other service providers and program administrators, have been approached for their opinions related to the development of housing and supports. Yet, studies that have compared the perspectives of caregivers, professionals and consumers about housing and support needs showed dramatically different results (Davidson, Hoge,

Godleski, & Griffith, 1996; Linney, Arns, Chinman, & Frank, 1995; Tanzman, Wilson, & Yoe, 1992; Young, & Ensing, 1999).

At the same time, in North America, consumers are beginning to both lobby for more normalized housing alternatives with flexible supports and they are demanding a strong voice in re-designing mental health systems (Carling, 1995; Goering, Durbin, Trainor & Paduchak, 1990; Nelson, Walsh-Bowers & Hall, 1998b). In addition, consumers' families, many whom have been the consumers' primary caregivers, are demanding residential alternatives (Hatfield, 1993; Morrissey & Este, 1997; Ridgway & Zippel, 1990). However, consumers have not been directly approached for their input and what is being offered is not necessarily responsive to consumers' needs and desires. What has been missing is twofold: (1) the involvement and participation of mental health consumers in sharing their experiences and indicating their preferences for housing and supports as they are the individuals directly affected, and (2) an examination of housing and supports through a broader lens where all types of housing that consumers live in is considered along with supports both formal and informal.

Undertaking research that asks consumers about their perceptions and preferences on housing and supports is one way for the missing voices of mental health consumers to be heard. Utilizing this focus in the current study, it is hoped that mental health policy and service delivery systems can become more responsive to the needs of consumers.

Research Questions

Huberman and Miles (1998) suggest that in order to clarify the empirical domain under study, research questions must be laid out. They emphasize that a set of defined questions, "represent the facets of an empirical domain the researcher wants to explore,

setting priorities and foci of attention and implicitly excluding a range of unstudied topics” (p. 204). Huberman and Miles indicate that the research questions may deal with “research, policy, evaluation or management issues” (p. 204).

In this study, the following questions were posited:

What are mental health consumer's perceptions of the housing environments they have experienced?

What are mental health consumer's perceptions of the supports that they have experienced?

What are mental health consumer's preferences for housing?

What are mental health consumer's preferences for supports?

Summary

This chapter provided the background for this study. A section on the North American context related to housing and supports was presented. Definitions of the terms regarding how people with mental health problems and their mental conditions was addressed. The history of responses offered to intervene with people with mental health problems was explored from both a North American and more specifically, a Saskatchewan and Alberta perspective. Theories of understanding the etiology of mental health problems and interventions, in conjunction with a critique of these theories were introduced. A review of the literature of housing and supports in the mental health area was undertaken. Finally the rationale for this study and research questions were presented.

CHAPTER THREE

RESEARCH METHODOLOGY

Introduction

This study aims to contribute to the emerging body of research as to the experiences and preferences of mental health consumer regarding housing and supports. In this chapter an outline of the methodology utilized for this research study is presented. Huberman and Miles (1998) indicate that despite the diversity of approaches to qualitative research, the minimal standards in a methodology chapter should include an articulation of: “sampling decisions, instrumentation and data collection operations, database summary, software used, if any, and an overview of analytic strategies followed” (pp. 201-202).

The first section includes a discussion of the rationale for a qualitative research design. Attention is next directed to an articulation of the research methodology and the specific procedures and techniques that were followed in this study.

Qualitative Research Design

The methodology chosen is based on a constructivist research paradigm as described by Queralt (1996). According to him, constructivists maintain that: (1) reality is not something objective but is socially constructed and (2) the notion of a single reality needs to be replaced by a perspective of multiple realities, where the meaning of each happening is perceived differently by each individual experiencing it. This paradigm stresses that each individual and social system has a different assumptive world and experiences a different truth. Hence, as Queralt has noted, “reality is shaped by the perceptions of each individual” (p. 7).

The ontology of this paradigm is that there are multiple constructed realities that can be studied and known and the epistemology is one of the knower and the known as interactive and inseparable (Lincoln & Guba, 1985). Thus the methodology is open in that it allows for a variety of methods to unfold (Lincoln & Guba). Mental health consumers are not an objective reality to be studied but come from a reality that is socially constructed. Each person's experience and context of that experience shape the consumer's assumptive world.

The qualitative research methodology is enjoying a resurgence in various disciplines including social work (Tutty, Rothery & Grinnell, Jr., 1996). Numerous kinds of qualitative research exist such as phenomenology, grounded theory, exploratory and naturalistic (to name a few) and each is embedded in different philosophies and approaches (Tutty, Rothery & Grinnell, Jr.).

The type of qualitative research utilized for this study derived from the exploratory approach and was theme-based. With there being little knowledge on the subject of this study, an exploration of consumers' perspectives was pursued with a thematic analysis of the data resulting. According to Coleman and Unrau (1996) some qualitative research studies use emergent themes and interpretations to contribute to or create theory while others present the themes that emerge from the data. This study followed the latter approach.

Qualitative methodology was specifically selected for this study in order to hear the voices of mental health consumers; that is, to elicit data entirely from their perspective. The perspectives of what is required for mental health consumers in the area of housing and supports have typically been left to the professionals, families and policy makers while little

has been heard from the consumer, the individual directly impacted by the available housing and supports (Morreli-Bellai & Boydell, 1994; Vandergang, 1996). Rothery, Tutty and Grinnell, Jr. (1996) indicate that when little is known about an area, “qualitative methods are well suited to provide exploratory information about possible needs and interventions” (p. 16).

As noted in earlier chapters, the past research on this topic most often has been quantitative in nature. However, researchers (Church, 1995; Hatfield & Lefley, 1993; Morreli-Bellai & Boydell, 1994; Strauss, 1989; Sullivan, 1997; Vandergang, 1996; Wilson, 1996) indicate that our knowledge in the area rests partially on our ability to understand the subjective experience of the mental health consumer, the expert on what their experience has been like. In contrast to quantitative approaches, the use of qualitative methods allows the respondents’ perceptions to emerge, rather than being pre-determined or framed by the researcher. A qualitative design provides depth, thickness and texture to the data (Rothery, Tutty & Grinnell, Jr., 1996; Wilson, 1996). This method is more adaptable than a quantitative methodology and allows for unforeseen data to surface and multiple realities to be constructed (Lincoln & Guba, 1985).

Sampling Procedures

According to Huberman and Miles (1998) “sampling choices within and across cases are powerfully determinative of just which data will be considered and used in analysis” (p.204). With qualitative research, obtaining data typically means utilizing a purposeful sampling technique. In purposeful sampling, cases are chosen to give the investigator access to some specialized perspectives or information rich data that sheds light

on the question under study and which facilitates expansion of the data (Yegidis & Weinbach, 1996).

Several limitations of the purposive sampling technique exist which may have impacted this study. For example, important key informants could have been missed or only certain types of informants represented. In addition, this study included only respondents from one urban centre, Calgary. Hence, it is not known if the results of this study would have applicability to the rural areas of Alberta. Indeed, experiences with housing may be dramatically different than those of consumers living in Calgary. In addition, although some similarities to the Calgary data may exist related to supports in the rural areas, these aspects would likely differ considerably, particularly related to the number and variety of supports available for the population.

Two key factors impacting the study's sample size were the concepts of saturation and that of research ethics. This researcher interviewed respondents until redundancy or data saturation was reached. Lincoln and Guba (1985) explain these concepts by stating that redundancy and saturation have been reached when categories begin to overlap, a recurrence of data is emerging, and the categories you hoped to collect data on have been covered. This occurred by the end of the fifteenth interview. However, five other interviews with consumers had previously been set up and the researcher believed she had an ethical obligation to meet with these interested consumers and complete the interviews.

Sample Selection Criteria

The research participants had to be at least 18 years of age, have a mental illness diagnosis and be a resident of Calgary. They had to be a user of mental health services, be

able to give informed consent to participate in the research study and be willing to be involved.

Accessing the Setting and Research Participants

According to several authors (Fontana & Frey, 1998, Rogers & Bouey, 1996), gaining entry into the setting for the purposes of data collection is the first phase of naturalistic inquiry. This process can vary tremendously but a number of authors stress the importance of having contacts or key informants to pave the way (Fontana & Frey; Rogers & Bouey).

This research required gaining access to adult mental health consumers in Calgary although at the onset of study, the number of respondents required was unknown. To this end, the author contacted an agency called The Calgary Association for Self-Help (C.A.S.H.), a large non-profit agency in Calgary that serves the mental health population. C.A.S.H. is both a self-help organization and an agency that offers a variety of programs including rehabilitation, counselling, an activity centre and a volunteer program. Ultimately C.A.S.H. tries to provide services that are based on the mental health consumer's needs.

The profile of consumers involved in this agency's services was diverse. They had a variety of mental health diagnoses and functioning levels, received various types of mental health services and were both female and male. They were all at least 18 years old and while the agency did not stipulate an upper age limit, consumers at the agency ranged in age from 18 to 70 years of age. At the onset of the research, the researcher did not realize that the majority of the individuals receiving assistance from the Calgary Association for Self-Help had severe and persistent mental health problems and that most were Caucasian.

The researcher knew individuals in senior administration at the agency, contacted them and set up a meeting. At the meeting, the research project was explained, points clarified and the researcher's need to have research participants from this agency was discussed. The agency administration gave approval for the research to be conducted there and the use of interview rooms, a telephone, and coffee was offered to the researcher.

C.A.S.H. runs seven groups, ranging from therapeutic to activity groups and each group has approximately 10-15 individuals involved in them. The contact person invited the researcher to meet with each of these groups to solicit research respondents. It was also clarified that these group members would be able to give informed consent regarding involvement in the research project.

The researcher explained the research project to the group members in addition to specifics such as the sample requirements, time commitments, location of the interviews, informed consent and the voluntary nature of the participation. From the seven groups at C.A.S.H., twenty consumers agreed to participate in the study and individual interview times were established.

Since a range of views was being sought, key informants who were not involved with C.A.S.H. but who were mental health consumers and recognized by either the staff or other consumers as being a source of relevant information were also invited to participate. Four additional respondents were obtained in this manner.

Data Collection

Each study participant consented to and was involved in an unstructured, face-face interview. All interviews were audiotaped. The length of the interviews ranged from one to

two and one half-hours. Two respondents required more time and a second interview was undertaken. All interviews were subsequently transcribed verbatim.

Authors (Denzin & Lincoln, 1998; Lincoln & Guba, 1985; Rogers & Bouey, 1996) point to a variety of data collection methods used by qualitative researchers, yet interviewing is one of the most common (Fontana & James, 1998). Structured interviewing, group interviewing and unstructured interviewing can be utilized to obtain data. The researcher used unstructured interviewing as the data collection method. This method is employed extensively by qualitative researchers (Fontana & James, 1998; Marshall & Rossman, 1995).

Researchers' experiences with such interviews indicate that there is a much higher response rate when face-to-face interviews are conducted (Yegidis & Weinbach, 1996). According to Sullivan (1997), face-to-face interviews are deemed to be an important means to hear the voice of mental health consumers. In addition, the quality and richness of data may be enhanced when using this interview method as the interviewer can hear the subjective view of the respondents and use probes to help respondents elaborate and expand on their responses (Babbie, 1992; Marshall & Rossman, 1995; Yegidis & Weinbach). Another consideration was the researcher's experience with interviewing, which lent itself to this data collection method. Marshall and Rossman (1995) indicate the importance of the interviewer having superb interviewing skills including the ability to listen effectively.

Marshall and Rossman (1995) warn that interviewing has its limitations. Respondents may feel somewhat inhibited or uncomfortable in meeting with the researcher face-to-face and sharing their perceptions. They also may be unaware of recurring patterns

in their lives. Interviews generate volumes of data that have to be analyzed and this is a difficult and time-consuming process.

Another possible limitation of this approach is noted by Tanzman (1993). She indicates that more traditional interviewers may create barriers and possibly defensiveness so data collected may not be as rich. With the researcher not being a consumer, this may have produced obstacles during the interview. However, the researcher was only aware of this being an issue in one interview that she conducted.

The literature indicates that interviewers, who are consumers themselves, can aid the process of undertaking the study as they are familiar with consumers' environments and consumers' difficulties (Carling, 1995; Church, 1995; Marsh, Koeske, Schmidt, Martz & Redpath, 1997; Morrelet-Bellai & Boydell, 1994; Vandergang, 1996; Wilson, 1996). Although hiring consumers to conduct the interviews was considered, after discussions with the researcher's committee members, the decision was made for the researcher to undertake the interviews.

Open-ended interviews focusing on the research questions evolved into a format referred to in the literature as an emergent design. Lincoln and Guba (1985) emphasize that "it is inconceivable that enough could be known ahead of time about the many multiple realities to devise the design adequately" (p.41). What unfolds in the interviews is a function of the interaction between the inquirer and the research participant, and is largely unpredictable in advance. According to Lincoln and Guba, "the inquirer cannot know sufficiently well the patterns of mutual shaping that are likely to exist and because the various value systems involved (including the inquirer's own) interact in unpredictable ways to influence the outcome" (p. 41).

All interviews took place in an office at C.A.S.H. The time period from setting up the interview to it actually taking place ranged from one to three weeks. With the exception of two respondents who were interviewed twice, all individuals had one interview.

Throughout the course of the weeks that the interviews were conducted, respondent participation was somewhat inconsistent. While 24 respondents had agreed to participate in the interviews, four did not attend their interview. In only one of these instances was the researcher notified ahead of time that a participant would not be able to make the interview. More commonly, the interview appointment was booked and the respondent did not show up. In retrospect, it may have enhanced participation rates if the researcher had obtained a phone number where the respondents could be contacted and then followed up with a call to remind the respondent of the interview. The length of time from when respondents agreed to be interviewed and when the interviews actually occurred may have been a factor associated with the non-participation.

Data Analysis

According to Coleman and Unrau (1996), the goal of the qualitative research study is to “understand the personal realities of research participants in-depth, including aspects of their experience that may be unique to them” (p. 90) and to “organize the information in such a manner that the words, thoughts, and experiences of the research participants can be clearly communicated” (p. 91). They emphasize that the purpose of data analysis is to “sift, sort, and organize the masses of information acquired during data collection” (p. 90) in a systematic way. Huberman and Miles (1998) call this data reduction, an essential component of data analysis in qualitative research. Qualitative research analysis involves inductive analysis, or “the process of uncovering embedded information and making it

explicit” (Lincoln & Guba, 1985). Their notions coincide with the other authors as they discuss beginning with unitizing and moving to categorizing.

Data analysis was conducted in a number of ways. Descriptive statistics (e.g. frequency distributions and means) were utilized to analyze the data related to each respondent’s age, gender, level of education, marital status, number of children and diagnosis. According to Westerfelt and Dietz (1997) the most basic level of analysis is that of calculating how many respondents gave a certain response to each question.

A research assistant transcribed the taped interviews verbatim. The researcher reviewed the transcriptions to reacquaint herself with the data. Coleman and Unrau (1996) support this process in their description of the importance of reviewing the transcripts of data to familiarize the researcher with the data obtained.

Qualitative data were examined manually using content analysis (Patton, 1990) to identify the emerging major themes. Content analysis consists of examining the data and deriving and organizing responses that are representative of predominant and significant ideas (Westerfelt & Dietz, 1997). Several authors (Lincoln & Guba, 1985; Marshall & Rossman, 1995; Coleman & Unrau, 1996; Westerfelt & Dietz) outline a blueprint for analysis of qualitative data. The process described by Coleman and Unrau (1996) was essentially followed.

First-level coding was achieved by identifying important experiences or ideas (meaning units or unitizing), putting them into categories and assigning codes. That is, meaning units or segments of information that were building blocks to category development were identified and then consideration of which of them fit together evolved.

This fits with several authors' ideas regarding first-level coding (Coleman & Unrau, 1996; Lincoln & Guba, 1985).

To exemplify first level coding in this study, the data obtained from respondent's experiences with formal supports they were receiving is used. Meaning units were underlined in the transcripts such as "I could stay in the program as long as I needed to and June (the worker) understood and never cut me off", or "The program even ran on Friday nights and during the weekend." From the analysis of these meaning units, the task was to consider which of them fit together. Categories that developed from the meaning units noted above were coded as follows: (1) accessibility of the program (2) the actual program offered and (3) factors related to the staff.

Second-level coding involved identification and refinement of categories from the first-level coding process. These categories were compared and contrasted with each other. Coleman and Unrau (1996) state that the primary task of second-level coding is to identify relationships amongst categories. Major themes and the relationships between them emerged, which is consistent with Coleman and Unrau's notions on the tasks of drawing meaning from one's data, namely developing conceptual classifications systems and presenting themes or theory.

An illustrative example of second level coding in this study related to a type of relationship amongst categories referred to in the literature as a causal relationship (Coleman & Unrau, 1996). Consumers that felt more satisfied with their type of housing reported on various factors that, if they were in existence, contributed to a feeling of satisfaction with their type of housing. Flexible eligibility requirements for housing,

affordability of housing, having formalized, flexible support available at their home and having permanent housing were examples of categories that related to housing satisfaction.

When the theme analysis was completed, the write-up of the results was commenced and the information was next presented in a written format. Individual responses representative of the major findings identified were cited to strengthen and enrich the discussion of the data obtained.

Trustworthiness of the Data

Unlike quantitative researchers, investigators using qualitative methods believe that the social world is one that is interpreted and not taken literally (Altheide & Johnson, 1998). The qualitative researcher seeks to capture the lived experience of the participants in order to make sense of their multiple meaning perspectives (Janesick, 1998; Wolcott, 1990).

One of the major issues for the qualitative researcher, therefore, has to do with ensuring that the data are trustworthy. This is a term used to evaluate the data and which replaces those of reliability, validity and generalizability associated with data in a quantitative research study. To reduce the opportunity for misinterpretation, various methods can be undertaken. In this study, to increase credibility of the data, the framework employed was the one presented by Lincoln and Guba (1985) and endorsed by Janesick (1998). Lincoln and Guba articulate four components that need to be addressed: credibility, transferability, dependability and confirmability.

Credibility

One way to envision and understand the concept of credibility is that there must exist the belief that the findings are truthful (Lincoln & Guba, 1985). In quantitative research the term used would be internal validity. Lincoln and Guba suggest a number of

ways to ensure the credibility of the data and some of these strategies were utilized in this study.

One strategy used to increase the credibility of the data was that of triangulation. This was accomplished in a number of ways. According to Stake (1998), triangulation “has generally considered a process of using multiple perceptions to clarify meaning, verifying the repeatability of an observation or interpretation” (p.7). Denzin and Lincoln (1998) confirm that triangulation is an alternative to validation.

The researcher had two individuals, one who was her committee supervisor, and another who was a researcher, read selected transcripts and code the data. A comparison was then made as to their results and the researcher’s, and a few changes were incorporated. Huberman and Miles (1998) refer to this notion as the peer reviewer or second reader, a strategy that strengthens the credibility of the data. This approach coincides with Lincoln and Guba’s (1985) concept of member checking, a method that has outsiders read the interview transcripts.

Another way that confidence in the data was increased related to member checking by the research respondents. Lincoln and Guba (1985) suggest that this type of member checking is one way to crosscheck our work by allowing participants to review the material. Respondents give feedback to the interviewer on the data in the written transcript and how it was coded.

Three participants were chosen to give this input and a copy of their specific transcript was provided to them by mail. They were asked to read the transcript carefully. The researcher subsequently met with them to obtain feedback on the accuracy of the data

and whether it represented their views, and the accuracy of the coding. Appropriate revisions were then made.

A second way that triangulation was employed to ensure congruence related to interpretations was that of interviewing respondents until the data became redundant or the saturation of data was reached. This procedure is one endorsed by Stake (1998) as another means to triangulate the data.

Journal recording was also used to enhance the credibility of the data. The researcher kept a daily log of all interviews conducted, and completed it after each interview or at the end of each interview day. These information records included observations on how the interviews went, to personal notations related to the interviewer's thoughts and feelings either about the interview or the administration of the research process. Additionally, at the end of each interview, if time permitted, the researcher discussed with the research respondents the interview process and suggestions they might have for changes. These were also entered in the journal. All of these observations were considered and some incorporated into subsequent interviews.

Transferability

Transferability, or external validity as it would be referred to from quantitative research, has been described by Lincoln and Guba's (1985), as involving the researcher's responsibility "to provide the data base that makes transferability judgments possible on the part of potential appliers" (p. 316). Similarly, Huberman and Miles (1998) discuss the importance of thick description of data so that other researchers can compare their research, undertake secondary analysis of the data, track fraudulent research practices, draw similar conclusions from the data, or replicate the study. However, it is recognized that with

qualitative research the latter is not completely possible because each researcher will interact with the research respondents in a unique manner.

Huberman and Miles (1998) refer to “transparency on the method” to make clear “explicit reporting of data and procedures” (p. 200). This researcher made the research process transparent by reporting in a detailed way on the research method. Sampling decisions, data collection processes, and data analysis were reported clearly. The researcher was specific as to how she ensured trustworthiness of the data. Finally, the detailed written report of the study, along with an articulation of sufficient rich description to support conclusions drawn, was provided.

Dependability

Several authors (Coleman & Unrau, 1996; Lincoln & Guba, 1985) refer to dependability as consistency of the research findings and their repeatability. Quantitative research would use the term reliability. Adherence to rigorous detail throughout the study, whether it be related to undertaking the interviews or decisions regarding coding is necessary to ensure consistency (Coleman & Unrau).

Coleman and Unrau (1996) outline several ways to ensure dependability. These include the researcher collecting the data, respondents participating voluntarily, clarity regarding coding indicated and receiving feedback from others on the interview content and coding. These ways were followed in this study.

Data were obtained firsthand by the researcher from the participants, a method that strengthens the information. The research respondents’ participation in the study was voluntary, another way to increase dependability. Decisions regarding coding were articulated clearly, a third means to ensure dependability. The process of involving others

(the researcher's supervisor, one other reviewer and selected research participants) in transcript review and coding, to see if they reached the same conclusions was yet an additional method to increase the consistency of the study's findings.

Confirmability

In qualitative research, the term confirmability has been defined as meaning the neutrality, objectivity or degree of impartiality that the researcher brings to the research process (Coleman & Unrau, 1996; Lincoln & Guba, 1985; McClelland & Austin, 1996). According to Lincoln and Guba (1985), the notion of confirmability replaces that of objectivity from quantitative research and the major technique for demonstrating confirmability is that of the confirmability audit. Audit trail categories include those related to raw data collection and analysis products, data reconstruction and synthesis products, process notes, materials related to intentions and dispositions, and instrument development information (Lincoln & Guba).

The researcher undertook a confirmability audit and used a number of the techniques suggested by Lincoln and Guba (1985). In this study, all interviews were audiotaped and observations about the interviews noted. A journal was kept that included a variety of pieces of information. Comments about the research process and themes that seemed to be emerging, personal notations and information to consider, and include either in subsequent interviews or at the time of data analysis were included. An outline of coding processes was recorded. Research findings with connections to the existing literature and an integration of concepts and interpretations were detailed. The audit trail utilized was consistent with the one recommended by Lincoln and Guba (1985) to establish confirmability.

Ethics

Before commencing this research project, ethics approval was received by both the Faculty of Social Work and the University of Calgary's Ethics Committee. The proposal submitted to them addressed matters of confidentiality, security of the data and consent. Regarding confidentiality, respondents were assured that their names would not be used in any documents that were written from the research but unique data could be included. Data would be stored securely for a period of five years.

Respondents were able to give informed consent, which was a sample selection criteria. Legally, in Alberta, any person over the age of 18 can give informed consent. Only persons certified to a mental hospital under the Mental Health Act or those persons deemed a Dependent Adult under the Dependent Adult's Act are not able to give informed consent. People designated under those two Acts were not included in this study.

Using the criteria described above, C.A.S.H. staff identified and determined whether potential research participants could give informed consent and all respondents referred for an interview were able to do this. At the time of the interview but before the actual interview commenced, the consent form was explained to each research participant and they were asked to sign the consent form in order for the interview to proceed. All agreed to do so. However, one interview was stopped when it became evident to the researcher that the consumer was too thought disordered to continue.

Conclusion

This chapter presented the methodology followed for this research. The choice of a qualitative research design was discussed. Sampling procedures including sampling selection criteria and limitations, and accessing respondents was indicated. Data collection

processes, data analysis and what was involved to ensure the trustworthiness of the data are reported. The area of ethics was also addressed.

CHAPTER FOUR

CONSUMERS' EXPERIENCES WITH HOUSING

Introduction

This chapter provides the findings related to consumers' experiences with housing. It begins with a demographic profile of the research respondents. Next the instability of many consumers' housing situations and the reasons why they move is examined. Types of housing that respondents have lived in are described and the major themes and sub-themes that were identified from the mental health consumers' experiences with these various types of housing are analyzed and discussed.

Of note for these consumers are the many issues inherent in locating appropriate, affordable housing and qualifying for it, and the location, size and condition of housing units. The importance of having permanency and a place to call home, concerns regarding roommates or living alone, and where support fits in with housing are addressed. In addition, having personal control in their living environments, the stress of some living situations and the stigma associated with some types of housing is discussed.

Demographic Profile of Research Respondents

A demographic profile of each respondent was assembled as part of the interview process. Twenty individuals were interviewed for this study. Selected demographic characteristics of the sample are presented in Table 4.1.

All research participants were Caucasian and the gender of the research participants was unevenly divided. 70% were female and 30% were male. Their ages ranged from 27 to 68 years with the mean age being 41.75 years. The most frequently recorded age fell into the range of age 35-39 years.

Table 4.1 The Demographic Profile of Research Participants**Demographic Variables****Respondents (n=20)****Gender**

Male	6
Female	14

Age

25-29	1
30-34	4
35-39	7
40-44	2
45-49	3
50-54	0
55-59	1
60-64	1
65-69	1
Mean Age	41.75 years

Education

Less than Junior High School	1
Junior High School	1
Some High School	4
Completed High School	5
Some Post-Secondary Education	3
Completed Technical School	4
Completed College Diploma	1
Completed University Degree	1

Marital Status

Never Married	7
Common-law	2
Married	0
Separated	2
Divorced	7
Widowed	1
Unknown	1

Number of Children

No Children	15
One Child	1
Two Children	4

No respondents were currently married. Two respondents were living with each other in a common-law lesbian relationship. Seven were single and two were separated. Seven were divorced and one was widowed. The marital status of two respondents was unknown.

Five respondents had children. All the children were adults with the exception of one who was a teenager and resided with his mother. Of those participants with children, one had one child and four had two children.

The education of the respondents varied considerably. One completed Grade 6 and one had some junior high school. Four had some high school and five completed Grade 12 as their highest level of education. Four respondents had attended college, university or technical school. One completed college, one possessed a university degree and three completed a program at a technical school.

In regard to diagnosis, one respondent had a diagnosis of an anxiety disorder and five had a diagnosis of schizophrenia. Nine had unipolar depression and five had bipolar disorder. Seven were diagnosed with a personality disorder, and six of these fell into the category of multiple personality disorder. Two were uncertain as to what their diagnosis was. Some respondents had more than one diagnoses. The respondents' diagnoses are presented in Table 4.2.

Although the consumers' sources of income and actual income was not directly solicited, nearly all the research respondents provided this information regardless. The vast majority of respondents were receiving the Alberta Assured Income for the Severely Disabled (A.I.S.H.). For most of these individuals this

Table 4.2	
<u>Respondents' Diagnosis</u>	
N=20 (some respondents have more than one diagnosis)	
Diagnostic Category	
Anxiety	1
Depression	9
Bipolar disorder	5
Schizophrenia	5
Personality disorder	7
Respondent did not know his/her diagnosis	2

amounted to \$823.00 per month plus coverage for specific medications, other health care and dental care. A few were receiving income support from Alberta Social Services and this amount varied depending on their circumstances but was less than those who were on A.I.S.H. Only one individual had a work related disability pension, and of all the respondents, she was the one who had the highest monthly income.

Housing Moves

A major finding that emerged from the data related to the precarious nature of the respondents' living situations, which meant that they changed residences frequently. While the consumers moved for a variety of reasons, the need for affordable housing was the primary reason. Other factors that prompted a move were the size of their residence, the location, and the quality of their housing. In addition, issues such as independence, autonomy, relational support, service support and housing authority policies impacted respondents' decisions regarding changing residences. Table 4.3 presents the reasons

consumers moved so frequently.

It was not uncommon for consumers to move two or three times in one year. Many others moved nearly every year. One consumer stated: "I've moved 12 times in 14 years because of stigma and safety."

Table 4.3

Reasons for the Frequency of Consumers' Moves

The Reasons

Unable to afford current housing
 Relationship problems where they currently live
 The size of accommodation
 The involuntary loss of accommodation
 Inappropriate accommodation
 Time to move from their parental home

Another commented on his many moves in a very short period of time:

I was at the group home from December 1 to January 22 and then I transferred to Claresholm from January 22 to April 9th and then I got home at my parents and I was there until about April 20th. Then I was at the Peter Loughheed until May 29 and then I was in a homeless situation. Then I was moved by my outreach worker for 2 weeks and then into my current situation where I live now. It's been a long drawn out process.

Most respondents lived on fixed incomes and they found the cost of moving expensive. The majority of consumers did not own a vehicle or have a driver's licence,

nor did their friends, so they had to hire a moving company to move them. If they moved to a smaller place, often they had to pay to put some of their belongings in storage.

The cost of the participants' housing was usually the driving determinant of relocating. With housing costs and rents in Calgary increasing, consumers usually moved as they required a cheaper place to live.

Frequently, consumers moved because they were given notice of a rent increase. One consumer's comments reflected those made by a number of consumers: "I was in an apartment but the landlord more than doubled the rent so I couldn't afford it." Another respondent said: "After 13 years my lease is running out and it will be too expensive here."

Some participants had held jobs, which was their source of income. However, when their mental illness interfered with their ability to function in their job, they lost their job and then had no income. As one said: "I had my own bachelor suite for 11 years when I was working but I had to move as I couldn't afford it (my apartment) when I no longer worked."

Another participant who lived in her own apartment for eight years tearfully explained why she left her apartment and how horrendous her move was: "I lost my job and I couldn't pay my rent. I got social assistance, which was \$400.00, and the rent was \$450.00. I lived without power for six weeks and I got evicted with only 2 days to move."

The few consumers with children, who were receiving financial assistance, moved when their child went to live with the other parent and thus their assistance was reduced. As one consumer described it:

I had a place when my daughter lived full-time with me but when she moved back to mom it became too expensive. Welfare was cut in half and I couldn't afford it so I had to move. For me and my daughter I was getting \$770.00 but then my daughter left and it went down to \$300.00 and some odd dollars. I had an offer of an apartment but I would have had to pay phone, cable and I needed a bus pass there so I couldn't afford it.

The size of respondents' living accommodation was sometimes a reason for moving. A few moved because they wanted a larger place or needed more space because of the number of people living in the house, and they were able to afford a larger place.

Some participants moved involuntarily. This occurred after they had been hospitalized, evicted, no longer met the eligibility criteria of their current accommodation or through the inflexibility of the policies related to services they wished to access.

A number of consumers moved after losing their apartments during a period when they had been ill and/or hospitalized. Either they were not functioning well enough to manage their personal affairs during this time (e.g. ensuring their landlord got the rent cheque) or they were cut off social assistance while in hospital. This was particularly distressing to consumers who often left hospital with no place to live and no idea as to what had happened to their belongings. Consequently they needed to find new accommodation immediately upon discharge and locate their possessions.

In many cases the consumer moved after having received an eviction notice. Some consumers, because of their lack of problem solving skills, their lack of supports, the poor state of their mental health, or the lack of affordable housing options, did not respond to the eviction notice until the final hour. This put them in a desperate situation.

They had to move, they needed accommodation immediately, and they had made no arrangements to either find housing or move. Compounding the problem was the shortage of housing options in Calgary and lengthy waiting lists. Consumers found this to be very stressful and often they ended up becoming ill and/or requiring a hospitalization during this time.

A few participants moved because they were in housing that had specific eligibility criteria attached to it, and they no longer met these requirements. For example, consumers with children had qualified for subsidized housing where there were two or three bedrooms. When their children reached the age of eighteen, they no longer qualified for a larger unit.

Two respondents were satisfied with their rental accommodation but found themselves moving because to access certain agency services, they were required to live at the agency's accommodation. This latter situation often proved difficult for consumers if they had been comfortable with their current living situation and they found the policy inflexible.

One consumer who had been in a very stable living situation described how problematic this policy was for her:

I had my own nice basement suite for 8 years and could afford it, but I had to let it go when I entered the program...to access the program you had to live there. Then when I get into the place, I find out the program is inappropriate for me.

Some consumers found themselves living in situations that were not appropriate and so they moved. One consumer's comments best illustrates this latter situation:

I was in hospital as an outpatient and then I went to the Y. I was required to be too independent and couldn't handle it as I had no skills and then I went back to my parents and then to the Women's Shelter. It was also inappropriate and then I went back to my Dad's and then to a residential program...and I didn't fit in and then I went to a group home.

Hatfield's (1993) research recognizes that the majority of adult mental health consumers live at their parental home. In this study most participants had lived at home with their parents during a part of their adult life but had eventually moved from their parental home for a variety of reasons. These included reaching the stage of adulthood when it is normal to move to becoming more independent, their family member(s) were no longer able to provide care to them, or they had relationship problems with their family and living there became untenable.

A number of respondents had been living at the home of their parents as they made the transition from being a child to becoming adults. Numerous respondents moved when they reached adulthood as they wanted to be more independent and have their own place, a development not unlike people in the general population. What emerged as differences with these respondents as compared to the general population though, was that both parents and consumers initially expected that the consumer would live at the parental home into adulthood, and when the consumers did move out on their own, they did so at a later age (e.g., late 20's and early 30's).

The major reason consumers lived at the parental home into adulthood was because their family member(s) provided care and support to them. In a few instances, the family caregiver was no longer able to look after the consumer and the consumer had

to obtain other living accommodation. For example, one respondent moved, after living with her mother at her mother's home, when her mother got ill and could no longer look after the consumer.

Research participants who lived with their parents or other family members sometimes moved because the living arrangement did not work out due to strain or abuse in the relationships. One consumer exclaimed:

I normally wouldn't have moved in with my daughter, but she just broke up with a boyfriend and she was suicidal. And she was pleading with me you know, please, please, please. So I finally gave in and moved in with her and within the month she was abusive to me...verbally, physically and financially so I had to find my own place. The doctor said I had to get out so I found a small, claustrophobic basement suite and my son and I moved in.

Many consumers found the process of moving very stressful. Usually consumers had no one to help them with their move and some left the move to the last minute. One respondent commented like this: "It's (moving) been very stressful and often I ended up being hospitalized at this time. Sometimes I was given little notice so it was very stressful to get the move organized."

Another vividly articulated her experience with moving:

It was very stressful...The caretaker gave me two days to get out. So I had to pack up everything in two days and get out. And by the time the two days was over, I was a basket case...And I was at the point of throwing away my possessions...That was really hard on me. I love to read and I ended up leaving over half of my books behind and on top of that trying to clean the apartment all

by myself, you know after everything was moved...I managed to find a company...that would come and take your stuff...to storage. But I still had to pack it up. I still had to move it up to the front lobby so they could move everything out...and that was something. And then I had to get myself down to the YWCA and booked in and everything. I was kind of vibrating rather badly by the time I got there.

Participants located accommodation in different ways. This depended on whether they were looking for market value or subsidized accommodation.

Consumers who were accessing accommodation that was priced at market value typically found the place on their own. They read the classified advertisements in the newspapers or, through word of mouth, obtained information that accommodation was available. Some had contacts with their family, and thus were privy to information that a relative or family friend had some type of accommodation that was available.

For those consumers accessing subsidized housing, they usually found out about it and were referred from an agency or a professional with whom they were already involved. In certain cases, an agency provided a variety of programs, including housing. A consumer might have been receiving different services from the agency and then discovered that the agency also had a housing program. In this way, they were asked to contact a worker in the housing program at the agency, and if they met the eligibility requirements, they were then put on a waiting list for the agency's housing.

When a consumer was looking for accommodation, choices regarding a suitable place to live were extremely limited. Appropriate, affordable accommodation was a rare commodity in Calgary and for subsidized units there were significant waiting lists. Often

consumers who were renting apartments received a notice of a rent increase. They quickly had to find accommodation that was at a lower price. Since cheaper accommodation was difficult to find, consumers found themselves renting the first place that they came across that they could afford regardless of what it was like

Those consumers who qualified and were on a waiting list for subsidized housing also thought they had to take whatever became available. One illustrative example of respondents' comments on this subject was this statement: "I moved in sight unseen as this was the only option. And it was a third story walk-up and I had arthritis." In other words, having a choice of accommodation that took into account important factors one would like to consider in ones living situation (e.g., space, location, condition of building, size etc.) could not be realized.

Commenting on this subject, a consumer exclaimed:

I was on a waiting list for 4 months and I had to leave my other place as the rent more than doubled and the landlord wanted me out to have higher paying tenants. He had said that he was tired of giving housing to people that are charity cases...he said I want to get rid of all the people that are in here that are on a fixed income. The landlord harassed me and he was on my case for 4 months every single week. I had to really exert pressure to get into this place. I had no choice but this place. And that's the other thing too. You get placed wherever you get placed... When I moved into here, I saw one apartment and that was it...That's the one I live in. I didn't get a choice. It's very, very small and it's a problem as I use a wheelchair and I can hardly move around in the apartment.

Experiences with Various Types of Housing

The mental health consumers interviewed for this study lived or had lived in a variety of types of accommodation: group homes, room and board, rented rooms, apartments, houses, basement suites, approved homes or their own home. Some participants had periods in their lives when they were homeless.

The majority of consumers believed their housing environment impacted the state of their mental health either positively or negatively. From an analysis of the data respondents provided, various aspects of a housing environment led to consumer's feeling satisfied with where they lived, regardless of the actual type of housing they lived in. These findings are presented in Table 4.4.

Rental Units (House, Apartment, Room and Board)

Nearly all of the consumers interviewed were living in some type of rental accommodation. This was their preferred type of living situation as opposed to residing in an approved home, group home, at home with their parents or in an institution. About one half of the consumers were renting a subsidized place which was either run by an agency that served mental health clientele or by a non-profit organization which was exclusively involved in providing housing. Others were renting accommodation and paying market value rents.

Subsidized Rental Units

Just over half of the consumers interviewed experienced living in subsidized accommodation. Two large non-profit agencies in the city managed most of these units and they provided housing to both people with mental health problems and others who were poor. A few other subsidized housing programs were available in the city and were

operated by mental health agencies that offered housing and a range of other programs for people with mental illness. Consumers expressed a variety of opinions about living in subsidized rental units.

Table 4.4

Aspects of Housing Leading to Consumer Satisfaction

The Aspects

Flexible eligibility requirements
 Affordability
 Appropriateness
 Quick availability
 Having a choice of housing
 Having a choice regarding roommates
 Having permanency
 Having formalized, flexible support available
 Having a feeling of personal control
 Having an adequate sized home
 Having a home in a good location
 Having a non-stressful living environment
 Having a non-stigmatized living environment

A number of respondents were concerned about the policies in place to qualify for subsidized housing. Restrictions related to where individual's income was derived or if respondents possessed pets were common. For example, the two largest non-profit housing organizations in Calgary did not allow renters to have pets. This policy caused great distress for some consumers and they would not apply for housing through these

agencies even though they were in dire need of a subsidized place to live. Respondents' pets were extremely important to some consumers as they often owned their pets for years, and their pets were significant factors in them enjoying their mental health. As one consumer stated who lived in a subsidized apartment and gave up her pet to move in: "No pets, that's a really big issue for me."

Another consumer who lived in subsidized housing gave up her cat to obtain her place. This is what she said:

There is no place that's subsidized that takes pets and that's a big problem. I had to give my pet to a friend. Now this cat is everything to me...She's the only thing I've got...That's the one thing that really bothers me about subsidized housing. They don't realize how pets can be so important to some people...I've had my cat for 14 years now and I'm rather partial to her.

Another concern regarding qualifying for some subsidized housing related to policies that limited where an applicant could obtain their income. For example, in order to be eligible for some subsidized units, one had to be receiving A.I.S.H. Consequently, those receiving social assistance were not eligible for these units.

The primary reason for living in subsidized accommodation had to do with cost. With the majority of consumers receiving a fixed income, having a subsidized place to live was the only way they could manage on their monthly budget. Even then, consumers receiving social assistance instead of the Assured Income for the Severely Handicapped (A.I.S.H.), faced a constant struggle to make ends meet.

A shortage of subsidized housing existed in Calgary. Distressing to consumers were the waiting lists to access subsidized housing. Consumers, on average, typically

waited six months to one and one half years to obtain this type of accommodation. However one consumer, who was in an emergency situation, got into a unit immediately and was very grateful for this. She said: “They managed to get me into a place right away. I don’t know what miracle she (a staff member the agency) pulled, you know, because there’s a waiting list.”

Consumers had little to no choice as to the subsidized unit they moved into. Since there always was a waiting for subsidized housing, when a consumer’s name came to the top of the list, they took whatever was offered. As one consumer put it when a place became available for them: “I had no place to live so I went there (a subsidized unit).”

The size of most subsidized units was very small and frequently these units were bachelor suites with no separate bedroom. The opportunity to rent a one-bedroom unit or live along in a two-bedroom unit was rare and occurred only when there were special circumstances. For example, one man was divorced and had joint custody of his daughter. He had access to her on weekends and so had been successful in obtaining a one bedroom subsidized apartment. However, this was still not particularly satisfactory considering she was a female and the unit had only one bedroom. When she was at her father’s place, one of them slept in the living room.

For many consumers, the small size of subsidized units made living there difficult. One consumer required the use of a wheelchair and the tiny size of the apartment presented problems. For a number of consumers, their furniture would not fit into the unit. This meant they had to sell it, give it away or put their furniture in storage, a cost they could ill afford. If they had to rid themselves of their furniture, they did so

reluctantly, because they knew with their limited financial means, they were unlikely to be able to purchase furniture again.

Others respondents found their unit very confining, and with having a mental health problem, a small unit was very difficult to live in. As one consumer remarked so graphically:

I don't think that bachelor suites are the best things for people. You know they're good for existing but they're not very good for living...You can't live in a bachelor suite. You can't turn around...It's good for living if you're out most of the time. But if you're indoors, you get claustrophobic...there isn't room for you belongings...it's just too closed in for a lot of people. You go there to sleep; you don't go there to live.

The consumers who resided in subsidized bachelor apartments did not have roommates. Some really enjoyed not having to share their home with someone else and felt good about being independent. Others though, spoke of the loneliness. As one consumer who lived on her own lamented: "I just can't figure out what to do about the loneliness."

When consumers qualified for and obtained subsidized housing they began to feel like this was home, often for the first time in a long while. For example, one consumer who was renting a subsidized 2-bedroom townhouse with her 16-year-old son, spoke very highly of her place, felt settled and indicated that her place felt like home after living there for six years. The woman stated that the rent was reasonable at \$345.00 per month, it was nice, had a backyard that was fenced, a garden, good neighbours; and the bus, shops and other services were very accessible.

However, this woman's major concern was for the time when her son turned 18. She would then no longer qualify for this unit unless she could pay the full rent of \$600.00 per month. The situation was compounded since she knew that when this occurred, her own social assistance would be reduced to \$800.00 per month. Already this consumer was gearing up for the "fight of her life" as she called it with the housing authority. She considered her place to be her home, she did not want to move and for the first time in years, her mental health was stable.

Consumers found that many of the subsidized rental units were older. While usually well maintained, they were often very basic and had not been renovated for years. Many had no carpet or the carpet that was there was the original carpet. Some of these smaller units had a bar fridge only and a hot plate but no oven. This was limiting for consumers as they could not buy groceries in any quantity (e.g. take advantage of sales or participate in a community kitchen), and they were restricted in how they could prepare their food. These consumers talked about having "fried everything" and how they had come to really dislike foods prepared this way.

Consumers were positive about the location of many of the subsidized housing units. A substantial number of these units were located in or close to the downtown core, and consumers liked being able to access the services and stores downtown. Some participants, though, identified that while being downtown was positive, often the subsidized units were located in a poor, or seedy area of downtown and they felt unsafe when they went out of their apartment, particularly in the evening. One participant noted: It's low income housing but there's a lot of violence that happens there (in that location)...There's always people getting beat up." Another consumer commented on

how: “The area was scary and unsafe.” A third respondent indicated that consumers were: “Regularly exploited by the bad folks in the area. They’ve had some drug dealers and they’re picking on some of the people who are ill and who don’t know any better...Some of the people with mental illnesses aren’t as knowledgeable on the kind of people that are down there.”

A few consumers commented on the stigma associated with living in a subsidized housing building when all units in the building were for people who qualified for a subsidy. As one consumer stated: “There’s a lot of people even in the normal community that knows what that building is.”

Subsidized Rental Units Offering Supported Housing

The consumers who lived in subsidized rental housing offered through a mental health agency were generally positive about their experiences. The primary reason was related to the fact that the agency also offered support services. In some instances this was a requirement of living in the specific apartment. Thus consumers felt that this type of living situation best met their needs, both as a place to call home and the fact that services were available, on an ongoing and flexible basis, to stabilize their mental health problems.

One distinctive theme emerged from these consumers. In supportive housing situations, the stability of their mental health and living situation vastly improved and was better when compared to any other living situation they experienced. One consumer enthusiastically emphasized: “There is great support from staff and that has offered me tremendous stability.” Another exclaimed:

It (supportive housing) does work well. It (the services) gives me stability which I never had before...It's a positive experience...It gives me what I needed in terms of something tangible to hold onto...My social worker is there if I need him. My case manager is there. I can call them up if I need them. I never had any of that ongoing support before and although I don't use these people very often right now, the very fact that they are there and that I'm able to call upon them is what offers me that stability. It's that framework that I can stand on.

Often in supported housing situations, consumers shared the subsidized unit with a roommate. Some described the opportunity to meet their prospective roommate ahead of time and noted this had been important to them. The age of an individual's roommate did not seem to be a major factor in deciding to share an apartment with this person. One consumer described a 30-year age difference between he and his roommate but commented that: "It works okay."

One important concern was raised about sharing a place with another consumer, relating to dealing with ones roommate when they were sick. As one consumer put it: "It actually works quite well until one of us gets maybe a little sick or something like that and then whole thing falls to pieces."

Respondents spoke positively about the fact that many of the subsidized rental units run by mental health agencies were also well located. They were usually within walking distance of shopping and services, close to a bus route and in a nice neighbourhood. Consumers felt safe in the building and this was related to feeling the apartment was in a "good neighbourhood", one that was relatively free from crime and violence.

When consumers lived in subsidized units run by a mental health agency, they felt like they had some permanency in their living situation and had finally found a place they could call their home. This was in contrast to policies at other places they had lived where one had to move out of their accommodation when they began functioning better, mentally, or they had exceeded the time limit allowed to live at the place. This notion of permanency was extremely important to consumers.

Non-subsidized Rental Units (Market Value Rents)

In Calgary, a major issue regarding renting accommodation at market value prices had to do with the cost of rental accommodation. At one time many consumers were generally satisfied with their rental accommodation, but found themselves having to find different accommodation when their financial circumstances changed. One respondent stated he always felt anxious about the cost of renting a place while on a fixed income. He stated: “\$350.00 is okay but if you have to start buying food on top of that then you run into problems.”

As mentioned earlier, about one half of the respondents lived in housing that was non-subsidized and yet the majority of respondents had a very limited income. Respondents lived in housing priced at market value for a variety of reasons. Some of these reasons were because the respondent did not know they had a choice between subsidized or non-subsidized housing or they could not exercise their choice, whereas other respondents made a conscious decision to choose accommodation at market value. Sometimes consumers were not aware of the existence of subsidized housing in Calgary. Others were on a waiting list for a subsidized unit and were paying full rent in the interim. Some participants liked the freedom associated with residing in their own place

and not having to contend with some of the policies or constraints associated with subsidized housing.

A number of consumers believed that renting their own place provided for stability in their living situation. They did not have to meet the requirements of subsidized places, and they could live at their home indefinitely if they wanted to and could afford to. A consumer commented positively when she said: "I've lived in this building 11 years."

The ability to keep a pet kept a few consumers living in rental units where they were charged full market value. However, sometimes there were extra costs involved if one brought a pet into an apartment. One couple described having to pay a pet deposit and stated: "Pets are allowed here but we were charged a pet deposit. I don't even know if it's legal to charge a pet deposit and we found out later that some people have pets here and weren't charged a deposit."

However, similar to respondents accessing subsidized units, a key theme from respondents looking to rent housing at market value was that of having little in the way of choice of affordable places to rent. Because of the high cost of rental accommodation and the fact that many consumers were on a fixed income, they usually required a roommate to share the housing expenses. While in some instances this worked out, for others having a roommate was problematic. One respondent told of her situation: "My partner and I have a two bedroom apartment but we share with a roommate to pay the rent...It's kind of crowded because one bedroom is given up for the guy that's living with us." One woman, in order to have someone to share the costs with, moved in with a

friend who was also her landlord. Their relationship became fraught with conflict when her friend (landlord) would not make necessary repairs to the unit.

Other consumers spoke of having to suddenly pay the total rent on their apartment after a roommate left without giving notice. They depicted this experience as financially and emotionally draining. One consumer described her situation in this way: “My friend (roommate) arranged to live with another friend and left me in the lurch, basically. My rent was \$390.00 and my welfare cheque was \$400.00 so I had to move back home (with her parents). It wasn’t great as my father was a perpetrator of sexual abuse (on me) so it was very difficult.”

Another echoed these comments when she described her situation: “I had a 2-bedroom apartment in this building and I had a roommate for 7 years. He left and I ended up owing 3 months rent, as I couldn’t afford the place by myself. Also the rent was going up to \$710.00.”

However, one consumer who rented a two-bedroom, two-bathroom, top floor of a house with another consumer whom she knew from before stated: “It was essential to have a roommate to share the rent.” However, this same consumer enjoyed having the company of her roommate.

When consumers could afford to live on their own, most chose this option and believed there were significant benefits. They enjoyed the freedom, autonomy and independence living alone offered them and they found this type of living situation extremely positive. One woman’s comments in this situation best reflect those of a number of consumers. She stated: “I like my independence. I realize it’s been good for me (to be on her own). It’s just better for me because I can live alone. I do not want

anybody living with me ever again...I'm capable...I really could not handle anybody living with me again...I'll take care of me and that's all that matters."

The condition of market value units varied. Some units were in reasonably good condition. For one consumer, his new apartment was: "The first decent place I've ever had." For another, her place was: "Nice, sunny, I grow plants, it's well kept and I can live by myself. My unit is big and spacious. It's great and I love it."

Many others indicated their units were poorly maintained. One man remarked: "I've had a variety of places...and thinking back on it, it was basically a nightmare some of the places I went to." One consumer described her apartment by saying: "It's old and crowded and it needs work. There's very old carpets and the walls need painting." Another respondent maintained that:

(It) was filthy, dangerous, (there were) bugs and it was very small. It's like a prison. You each got one room with a little bar fridge and a sink, counter and a cupboard. You've got to share the bathroom...(It was) disgusting, bugs, roaches, scabies, lice and crabs, you name it.

One consumer's story about the living conditions of her market value unit mirrored those told by many:

The place was awful, no running water in the suite nor a bathroom in the suite. The bathroom was on another level. And the landlord was to fix all that but never did...And another one bedroom place I had, I shared and slept on the couch. It was really gross, totally wrecked. Basically the carpets were soaked with alcohol...There were cockroaches.

Another described living in terrible rental accommodations: ...(There was) the noise. I was sleeping on a mattress in the living room for awhile. I was sleeping on a rubber mattress in the basement for awhile...and noise like you wouldn't believe.

Because most consumers were on fixed incomes many rental units that they could afford ended up being in unsafe areas of the city. One consumer, who was a lesbian, described a terrifying experience that occurred in the area she lived: "We were living in a bad area ...I was approached by a man on the street who held a knife to my stomach and said how would you like to have a hysterectomy you fucking dike...As well, a lot of break and enters and a lot of theft." Another respondent was raped by a stranger in her neighbourhood.

Other respondents also felt unsafe where they lived and they mentioned the criminal activity they were exposed to. One participant remarked: "It was disgusting. People were using drugs, coke heads and crack heads wandering the halls with needles hanging out. Another consumer indicated that: "There were drugs, violence...stuff like that...and I got sick and was hospitalized."

Consumers who could afford to rent a non-subsidized had some choices as to the location of their rental unit although they often also had to find a place quickly. One consumer remarked: "It's a good location, I can walk downtown and it's safe and secure." Another exclaimed: "It's a great location as it's right downtown. It's close to my doctor and dentist. I catch the C-Train to get groceries."

Consumers frequently indicated that renting a unit that was not subsidized invariably meant it was larger in size. They enjoyed the fact that they could have their

own furniture and because their places were usually larger than the subsidized units, that their furniture would fit into the unit and appliances were full-sized.

A number of consumers experienced difficulties and or abuse with their landlord but felt helpless to do anything about it. While they were capable of living on their own, often they were uncertain as to how to respond to their landlord and what their rights were. One consumer described her experience and that of her partner after renting a new place:

We were abused by our landlord. He took our \$150.00 deposit and kicked us out the same afternoon and said I'm keeping your downpayment and when we said why, he goes, you're just a bunch of freelunchers. He says you want to move in and stay on social services...He says I don't want your kind around here. Then I said give us back the \$150.00 deposit that we gave you yesterday. He said no, I'm keeping it. What can you do?

Another consumer's comments reflected incidents with which others had experienced:

"He (the landlord) came over unannounced when you're supposed to give 24-hour notice as a landlord. He entered the apartment, he was being very aggressive, swearing, yelling, pointing his fingers in our faces, abusive. He was finding reasons for eviction." In this instance, the consumer was unsure what to do.

It was not uncommon for landlords to not follow through on maintaining a unit a consumer was renting. Some landlords made changes to the cost of the rent soon after a consumer moved in. Consumers felt vulnerable and powerless to deal with these situations effectively.

One consumer moved into a place where there was no running water in the unit and she had to use the bathroom and do her dishes, upstairs, in another place. This was to be fixed when she moved in. As well, the consumer was paying the amount of rent on the unit charged by the landlord but when her fiancée moved in too, the landlord increased the rent for the unit. This is what the consumer said:

It was reasonable to expect to pay the rent...and when my fiancée moved in, she said, oh well, he can pay rent too, can't he? And you know it's like, excuse me, there's no water or bathroom in this place. But me being insecure and not wanting to lose the place, because you know I was thinking, where would I go, what would I do type of thing, I didn't want to move back home. The way I was feeling I wouldn't say anything. Like you know I was basically and totally non-assertive.

Room and Board

A third rental option for consumers was that of living in a room and board situation in someone else's home. The homeowner provided a bedroom, access to some other parts of the house and meals to the renter in exchange for a certain amount of money.

Only one consumer interviewed lived in a room and board situation. He lived with a family in a 4-bedroom townhouse, had his own room and cooked his own breakfast and lunch. The woman from whom he was renting prepared the evening meal. He moved to this type of living situation after he lost his job and could not afford his old apartment. This individual lived here strictly because of the cost, \$350.00 per month.

This man spoke about the difficulties associated with room and board, such as living with others and sharing a bathroom. He did not feel like his room and board situation was home. Often his landlady spoke of moving, leaving the consumer feeling uncertain as to where he would live. This was stressful and he also felt anxious because he had been told of a 4-year waiting list for subsidized housing. Compounding the problem was the consumer's realization that he could not enter the regular rental market as he could not afford it.

This consumer also mentioned that the townhouse where he lived was poorly maintained, noisy, and that the building was not safe and secure. However, the location and access to the bus and shopping was very good. Additionally, the consumer despaired that, although dinner was provided, the quality of this meal was: "Very poor, awful to be exact. There was no variety or choice and the lady is a poor cook. I don't know if she is trying to ease us out with her substandard cooking."

A Rented Room

A small number of consumers had lived in a rented room in a rooming house, hotel or at the Young Men's Christian Association (Y.M.C.A.). Renting one room in a hotel typified this living situation. There were usually no cooking facilities and one shared a bathroom down the hall.

The inexpensive cost of this type of accommodation was the primary reason people lived there. One participant stated: "I lived in a rooming house for 10 years at a cost of \$325.00 per month. Another respondent moved into a hotel room after being discharged from hospital with no place to go. The cost of the room was the main reason for renting this room and he paid \$250.00 per month.

A few consumers needed temporary short-term accommodation while they were looking for a more permanent place to rent. In this sense, the Y.M.C.A., a hotel room or a rooming house provided a place to stay where the consumer did not have to make a long-term commitment.

All consumers reported on the very poor living conditions in such places. One consumer reported living in a hotel, which he referred to as a “slum hotel room.” He described the conditions of this hotel and room in this way: “I have a mattress on the floor and some broken down furniture. There are no cooking facilities and I share a bath down the hall but it is too filthy to use. It’s unsafe there and it’s noisy and there are drunks.”

Another respondent said this about renting a hotel room after being homeless: “We lived in a van for awhile and we finally got a bit of (financial) assistance. We shared one room with eight people who had also been homeless... It was just a room with a sink and a fridge and a stove and the bathroom was down the hall. It was dangerous.”

Another respondent described the living conditions in rooming houses where he had lived in this way: “The rooms were dives, shared baths...drugs and alcohol and mental health problems.” One woman said this about her experience: “I had one small room for 10 years. I shared a kitchen and bath. The food was your own but it was locked in the kitchen cupboards so your food did not get stolen.”

Living in a rented room was stressful for consumers. One participant said this regarding the stress associated with this type of living environment: “(It) was difficult and awful. I had my own bedroom, no cooking (facilities), a shared frying pan, the showers worked poorly and it was not clean...My worker managed to get me into another

place. Otherwise I would have ended up on the street. I was not eating. All month I hadn't been eating that much. I lost about 40-50 lbs. when this was all going on. I ended up getting sick and attempted suicide.

Respondents who experienced this type of living situation reported feeling hopeless that their situation would ever get better. One woman indicated: "I had no expectations of a better life. I just accepted that this was the way it was."

Group Homes

Most Calgary consumers interviewed experienced living in a group home. Usually these homes housed four to eight individuals with mental health problems or other difficulties and were operated by a non-profit agency or private agency. Depending on the clientele, group homes had staff working during the daytime, evenings, overnight or had 24 hour per day staff coverage.

Placement Issues Related to Group Homes

Research respondents referred to being "placed" in a group home setting. What was implied was that group homes were temporary living situations that were not home.

A frequent concern about group home living focused on the appropriateness of the placement. One consumer with asthma was placed in a group home with smokers. She said: "I'm asthmatic and they set me up with a smoker and I specifically told them ahead of time, like I can't be with a smoker." Even with her health concern being identified prior to her move, she was still placed in a group home with smokers. She ended up having to move again shortly thereafter.

Another participant believed the group home where he lived was not suitable for him. Previously he lived all his life in a rural community, married, had children, was

employed in a well paying full-time job and contributed to the running of his household. When he got sick, and needed additional support, living options for him in his rural community were non-existent. Consequently, his service providers believed that a group home in the city would address his needs.

These were his comments regarding the suitability of living in a group home in Calgary:

I had to change locations and change doctors and then change from rural to city life. It's been very difficult as my son lives in the country with his grandmother. I can't afford to call him or go see him. My friends all live in the country too. They don't come to the city and I don't get to see them.

Additionally, he believed that he was quite different from his roommates and felt this was not a compatible arrangement given these differences. As he remarked:

My roommates come from a very different background. I was raised in a loving family but they are very hard as they were raised on the streets. As well my one roommate is very messy and doesn't clean up...I don't want to pressure her with it because it makes her mad and then it causes hostility in the house. And she tattles to the resident manager so it's very hard to live with her.

A third issue for this man related to the appropriateness of group home living was that his self-help skills were at a higher level than others at the group home, and that secondly, services were provided to him which curbed his independence. For example, one service that was included in the cost of living at the group home was that the group home manager shopped for the residents' groceries. The respondent noted that: "The

manager buys the groceries and that's inappropriate as I used to do that myself. I'm much more independent than the others in the group home are."

Issues of Personal Control in Group Homes

Many respondents did not feel that group home living was home. A frequent concern about this environment was the lack of control consumers experienced over their daily lives, which resulted in dissatisfaction with group home living.

Where group living was an option, consumers wanted to at least meet their prospective housemates. This was indicated not only by those moving into a group home but also by those individuals already at the group home setting. When considering moving into a group home, most consumers were given the opportunity to visit the group home ahead of time and meet their potential roommates and they were pleased about this. However, one respondent lamented the fact that he had not had a pre-visit to the group home before agreeing to move there. Sight unseen, he had moved into the group home and begin living with total strangers. He also was required to sign a six-month lease, prior to moving in, at a time when his income was very uncertain. This consumer commented on the inflexibility of the group home policies and his lack of control over this important part of his life.

At one group home, when there was a vacancy, the consumers who resided there were able to interview prospective group home residents. Although their experience was rare, when it did occur, consumers were extremely encouraged and liked the fact that they had some control about whom would be living with them. In this regard, one consumer stated enthusiastically: "We had the freedom to choose our roommates and this was

important. It was the first time ever that I got to pick my roommates. We interviewed about five people because we wanted to be sure we had a good roommate.”

Consumers complained about difficulties associated with living with other consumers in a group home. A number of respondents found the gender mix to be an issue for them, particularly when there was more males than females. One consumer remarked: “I was the only female with seven males.” Female respondents felt the males dominated the living environment.

For others the sheer number of people one had to live with was a problem and they found the relationships with other residents strained and hard to contend with. As one consumer stated: “I couldn’t live with that many people.” Consumers often found themselves getting into conflicts with other group home residents, particularly if a resident was ill. One consumer said of a consumer at her group home who was mentally unwell for a period of time: “(He) would be offensive when he was not well.”

Another consumer had lived on her own after having lived in a group home for a number of years. Her worker and psychiatrist were now encouraging her to return to group home living. However, she cited a number of reservations: “It’s hard to live with others and you lose your independence but I need the support. I don’t know after living so many years on my own that I could live with a group of people...And when I’m under stress I have a tendency to get a little cranky too....”

Others identified the lack of privacy when living at a group home. One long term group home resident put it this way: “That’s one thing that goes part and parcel with living with a group of people is that you lose, I see it as a loss of privacy, You can’t go walking around the house in your underwear.” Another who had a weight problem found

that other residents felt free to comment on the amount of food she ate, again an invasion of ones privacy and very disconcerting. She stated: “Everybody was calling me on my eating. I was feeling picked on to be very honest.”

Consumers felt some personal control related to their living situation when they had their own house key. As an example of this, one participant spoke positively about having his own key to the group home. He liked the idea that he could come and go as he pleased.

Another aspect of having personal control while living in a group home related to having ones own money. At some group homes, the staff were in charge of the consumer’s money. One consumer identified feeling vulnerable and at the group home manager’s whim regarding her social assistance cheque. She said: “She (the group home manager) had all my information and all my cheques going to the address of the group home. I did not have direct deposit and I would have to wait until she (the manager) chose to give me my cheque.”

The preparing and consumption of food along with residents’ smoking were often areas about which personal control issues arose. Overweight consumers were often required to be on diets if they were living at a group home and they resented this very much. Staff usually emphasized the importance of this in light of health concerns and they felt free to restrict the consumer’s food intake. One respondent remarked about the double standard associated with those consumers who had weight problems and whose diet was restricted and those consumers who smoked. She highlighted this issue by saying: “There’s definitely a double standard. Like they (the staff) say you’re gaining

weight, you're eating yourself to death...but yet nothing is ever said about their (the other residents) smoking."

Most group homes had various policies residents were required to adhere to in order to live there. Typically these related to consumers having to set goals and work on them, be in attendance at a day program or follow various house rules. Many respondents indicated their dislike of these types of policies and rules. As an example of this, one respondent was told by her group home manager that: "I'd better get working on my goals or I'd have to move. The manager said: "We'll put someone else in your place." The consumer lamented that: "It's your home (and yet) if you're not working on your goals than the feeling is why are you there?" Another consumer remarked about the inflexibility related to group home living when she was told this: "I had to be attending a day hospital to live at the group home which meant I also had to have a different psychiatrist." Others spoke of finding the group home rules restrictive. One consumer, engaged to be married, spent considerable time with her fiancée at the group home. This was not allowed and the consumer ended up having to move out because she did not follow the rules.

Staff Support in Group Homes

Consumers spoke positively about having staff available to them at a group home. These consumers felt that they needed the support of staff and the structure provided in this living situation. One consumer who resided at a group home when she was younger, commented that: "I was new to the system and I needed this support and information. It was great there. I needed that at the time...because I didn't know anything about mental

health services and I didn't know about therapists and I needed that time in a group home to heal."

Another participant said this: "We had 24-hour staff who were good. There was this lady...she worked there and she calmed me down a lot of times...she would put on nice music...Then I felt better when I could talk to people (staff)." Another stated: "The staff are good, caring and compassionate, very considerate...And she (a certain staff member) talks to you as an equal. She doesn't talk down to you."

In the same regard, one woman considering a group home mentioned this:

...But it's the lack of a support system...They (staff) wanted me to go into the group home just to give me the support and not to be alone. Now going into the group home again that would be nice to happen because I haven't had the support. I haven't had the pats on the head. I haven't had that little bit of spoiling.

Stigma of Group Homes

A few participants identified that group home living was stigmatizing. One participant worried about the stigma and said this: "...And group homes have a bit of a stigma to it too, that is you have to be in really bad shape to be living in a group home and to me the idea of thinking that I was in that bad of shape, I didn't like that idea."

Approved Homes

While no respondents were currently living in an approved home, a small number had lived in this type of living environment. Approved homes are a living situation where one lives with a family who are paid to offer support, structure and training to the

consumer while at the same time providing accommodation. In most approved homes, consumers had their own bedroom and had some access to the rest of the house.

Consumers were quite negative about their experience living in approved homes. They felt it was not their home and that they were at the mercy of the family who might have restrictive rules or decide to move, regardless of the wishes of the consumer. As one participant articulated:

They're not the shelter from the storm that they would appear to be. I've heard of people moving into an approved home and finding out a couple of months later that the lady who runs the approved home is selling her house...You're a guest in their home...There are times that if they don't want you in the house during the day they'll tell you not to be in the house...and they won't give you a key to the house.

Home Ownership

It was rare that consumers owned a home. However, two respondents were homeowners. Of these, only one actually lived in her own home, a three-bedroom condominium. She also was the only consumer who had a disability pension through her employer and, thus, her financial situation was better than all the other respondents. Of the consumers interviewed, this consumer was the happiest with her living situation. She described her home in very positive terms saying it was: "Sunny, bright, in good condition, it's a good location and my mortgage and condo (sic) fees are only \$560.00 per month. I love living alone. I have good access (to shopping and services) and it's a good location."

However, while this participant spoke positively about having her own place, it did not come without its problems. Her main problems related to the upkeep and the lack of response from the condominium management board in attending to her complaints. She stated: “There were many problems with the building, the sewer would always back up, it had a leaky roof and sewer gas and I had to fight for repairs.”

Another respondent owned her own home but did not have access to it and was renting another place. Her situation was unique in that she had inherited the house and had lived there with her husband and children previously. She was now separated from her abusive husband, and had left the home because of the abuse. However because she was on a fixed income, she could not afford a lawyer to initiate divorce proceedings, child custody matters and resolve the property issues. Unfortunately, although she had no access to her home she did not qualify for subsidized housing because she owned this home. As she so graphically commented:

I want my own place but I don't qualify for subsidized housing as I own my home but it's occupied by my abusive husband. Because you own a home, they can't help me. You've got to be broke, no money at all...So that's sadness for women who have husbands who are abusers and where the women owns things. They get no help. You just have to tough it out and somehow to get out on your own. You've got to be dirt poor or no money or assets before they'll do anything.

Those respondents who had owned a home before had usually been married and/or working. They spoke of their housing situation at that time in positive terms. However, they described losing their home through unemployment, illness, divorce and lack of the ability to access legal services to protect their interests in their homes.

Homelessness

A number of consumers experienced homelessness, living on the streets for a period of time. Often this resulted from having to move from where they were residing and then not being able to find accommodation or not having enough money to access accommodation that was available. One female consumer's comments mirrored those spoken by many: "I lived on the streets for years. I had no money, no roof...It was hopeless." Others talked about living in their vehicles and learning where you could get free meals and showers in the community. Another spoke of coming in conflict with the criminal justice system while living on the street. He stated: "I was on the street on my own. I stole food to survive. I had no source of survival (income)." One male lived on the streets and only moved from there after he was befriended by a family and taken into their home for eight months.

Summary

This chapter began with an introduction and a demographic profile of the research respondents. The data presented here exposed the precarious nature of mental health consumers living situations, how often they moved and the reasons for moving. Various types of housing environments that consumers lived in were identified. These were rental units, both subsidized and non-subsidized, supported housing, room and board, rooms only, group homes, and home ownership. Some respondents had been homeless.

Common themes that emerged related to respondents' experiences with housing were those of lack of choices for housing, inappropriate accommodation and locating accommodation. For rental housing including renting a room, sub themes regarding eligibility requirements, cost, lack of availability, size, roommates, living alone, a feeling

of home, living conditions, safety issues, location, landlord difficulties, and stigma were mentioned. With supported housing, participants noted sub-themes of support issues, roommates, location and permanency.

For respondents living in room and board situations and group home living, additional sub-themes emerged. Loss of control, quality of living conditions, cost, a need for short-term accommodation, stress, placement issues and staff support were all noted. Those who owned their own home were the most satisfied.

Some participants had periods in their life with no accommodation. These individuals ended up homeless and living on the streets.

CHAPTER FIVE

CONSUMERS' EXPERIENCES WITH SUPPORTS

Introduction

Although the conceptualization of supports has, in the literature, taken on various meanings, in this study supports were the formal and informal assistance required by mental health consumers to function at their fullest potential in the community. All consumers interviewed received an array of services and supports related to addressing their mental health needs.

Services identified were in-home support services, counselling, life skills, homemaker services, mental health services, crisis services, physician services, self-help services, outreach services, drop-in centre services, clubhouse services and medication clinic services. Other formal supports identified included financial, employment, educational, leisure, transportation and legal supports. Consumers viewed formal supports that would assist them in their rehabilitation and recovery in a broad way that went beyond the traditional thinking of medical services as the main area of need.

The importance of informal support systems was also identified and consumers included their families and friends in this category. Associated issues in these relationships were discussed.

In this study, consumers were able to clearly articulate their experiences and satisfaction with the supports they received and clarified factors that contributed to the supports being helpful to them. Regarding formal supports, the fact that a program or service was available to consumers was only a beginning. Factors related to accessing a

program, factors of the actual program itself, factors related to the staff, experiences with physicians and specific aspects of support were all important dimensions of consumers' satisfaction or dissatisfaction with formal supports. The nature of the relationships with informal support systems also contributed to or detracted from consumers feeling satisfied. These dimensions of supports are discussed next.

The Formal System of Supports

As indicated above, consumers received various programs and services to assist them with their mental health difficulties. These were usually offered under the auspices of an agency or organization operating in the community. Physicians also provided a number of support services. A few services were received from other professionals in private practice.

Factors Related to the Program

Participants identified a variety of general themes related to the formal programs and services they were receiving. These are presented in Table 5.1.

Accessibility of a Program

Respondents mentioned many access issues related to the programs in which they were participants. The hours of the service, location, waiting periods, cost, comprehensiveness, mandate and staff attitudes were all dimensions associated with accessing a program or service.

Consumers liked programs and services that they could access easily. Programs with flexible hours, that is hours that were outside the traditional 8:00-4:30 p.m. weekday hours of some agencies, which were available on weekends as well, were regarded positively. For example, one new downtown health clinic was open 24 hours a day and had

Table 5.1**Formal Supports – Aspects of a Program Leading to Consumer Satisfaction****The Aspects****Accessibility of the Program**

Flexible Hours of Services

Good Location

Immediate Accessibility to Services

Affordable Services

Comprehensive Services

Broad Mandate of Service

Positive Staff Attitudes to Consumer Accessing Services

The Actual Program Offered

Program Not Time-Limited

Comprehensive Community Services

Flexible Programs

Program Variety

Openness Regarding Program Information

Factors Related to the Staff

Staff Qualities

Caring, concerned, supportive

Strong listening skills

Staff who were not controlling

Staff skilled at transitions

Reliable staff

Staff Skilled in Dealing with a Range of Consumers and Consumer Behaviours

Staff Knowledgeable and Experienced

Staffing Consistent

mental health workers on staff. Every consumer interviewed who had attended this clinic remarked on the accessible hours and how this was a major factor for them in going to this clinic for services.

Consumers were most satisfied with a service when it was located close to where they lived. A number of subsidized housing units were in the downtown core and consumers that lived there were very pleased with a new health clinic that opened downtown. For others, the location of some of the services they required was in areas of the city where they felt unsafe. One participant said this: “(It) was a good agency but it was too scary. With the neighbour and the street people, I didn’t fit in.”

It was most desirable for consumers to be able to access a service they required immediately. A predominant theme from Calgary consumers was the length of time required to actually receive a service after initial contact was made. Nearly all of the respondents spoke of long waiting lists and how difficult it was for them to wait for a service when they needed it now. One consumer who was waiting to get into a therapy group noted: “It’s 1 1/2 year waiting list for the group.”

The notable exception to having to wait a long time for services was with community crisis services in Calgary. Consumers accessed these services in a time of crisis and were seen almost immediately. One consumer stated: “I was suicidal and I was seen quickly. The therapist was good and helpful.” Another echoed these remarks by saying: “I called when I was suicidal and was referred and was seen right away.”

For other consumers, it was not the agency that had a waiting list, but the agency providing the funding for the service, that made accessing the service a long, involved process. As this consumer remarked:

I had to go and jump through so many hoops in order to get him as my therapist because they (social services) don't like private therapy...I had to be diagnosed here in Alberta, although I had been previously diagnosed by a world renowned psychiatrist in Nova Scotia. It wasn't an Alberta diagnosis. I had to have four letters recommending this therapist before they would allow it.

A number of agencies, who did have waiting lists for certain services, still offered clients other opportunities to be involved with the agency while they were on the waiting list, and consumers spoke positively about this. In this way, consumers felt some connection to the agency and workers and were not left without any service in a time of need.

A number of services were free and those were usually ones that were offered by a government agency or government-funded agency. Other agencies charged a fee for service, although some had a flexible fee arrangement with fees contingent on ones income (a sliding scale). Still others charged a professional fee (e.g., \$100.00 per hour) which was out of range for consumer on fixed incomes. Thus the cost of a service was a factor related to a consumer obtaining that service. With many respondents on fixed incomes, even a minimal charge for a program sometimes prohibited one from receiving a service. As one said: "I would really like to attend the...group but I can't afford it as there is a small charge."

Those services offered by private practitioners were generally unavailable to consumers on fixed incomes and yet often these were the services the consumer required. As well these services were less likely to have a waiting list. Some agencies required one to live in their residence to access their service for free, and if the consumer moved out of

the residence, the service was either discontinued or the consumer had to begin paying for it. One consumer said: “My counsellor...for my M.P.D. (multiple personality disorder) was great but I must pay for this now as I no longer live there.”

With budget constraints, which translated into fiscal and human resource constraints, most agencies had limits on how much service they could offer a consumer. This made it difficult for consumers who often wanted more service than they could actually obtain. As one consumer related: “I had a good counsellor but she had limited time for me so she could only do so much in that period of time.”

A number of consumers experienced frustration with the specificity of the mandates of certain agencies or with the fact that the mandate changed while one was a consumer there, often resulting in the consumer having to leave the agency. One consumer who was refused service at a government run mental health agency felt very resentful: “It really bothered me when they said they couldn’t help me. It’s like that’s the major mental health agency (in the city) saying you’re hopeless, go away, we don’t want you. That’s exactly what it felt like and they were going to try to get me a psychiatrist and that never happened and it fell through.”

While there were a large number of different service providers in Calgary, consumers felt that some were more accessible than others due to the attitudes of the staff. On occasion, this was related to stigma consumers experienced from the staff in a program. For example, one lesbian couple, both with mental health problems, had difficulty obtaining service from a crisis agency once the staff found out their sexual orientation. As they indicated:

These two (workers) came to the door...as outreach workers...They sat there and I start telling them about hallucinations...and the next thing I said, by the way either of you guys aren't homophobic are you? And he looked at me and was kind of glancing around the room. She looked kind of upset, nothing else was said...and they took off and the next thing I know (by phone), they said we have a problem concerning your sexual orientation...Boy was I mad...He said he was kind of uncomfortable with our situation, with our relationship and that they usually go out in twos. Where at the beginning they had said whomever you feel most comfortable with (was who you could see).

The Actual Program Offered

Consumers had been involved in numerous programs and they identified various aspects of a program that they found helpful or problematic. Programs that were not time-limited, were comprehensive and community-based, were flexible, had variety and where program information was readily available were all features of programs that respondents found desirable.

Participants frequently found that programs with no time limit best met their needs. This program aspect related specifically to the nature of their mental illness and the fact that, at times, they needed a service, at times, they did not, and at other times, they needed only limited hours service. One consumer stated: "Here, you're in as long as you want to be and that the program fits for you. There's no limit on how long you can be in the programs or how many programs you can be in or the length of time you can attend the agency." Another respondent at the same agency commented: "The group is open-ended so you can attend as long as you want and I like this very much."

Often consumers expressed frustration with the time limit on the treatment modality offered. One consumer's comments reflected those noted by many: "The agency was warm and supportive but the program was time-limited. It only ran for 3 to 4 months and this was a problem. I had to terminate but I was not ready."

Respondents were particularly positive about programs that were both community-based and comprehensive. Programs that addressed both the physical and mental health needs of respondents at one location were well received.

For example, all consumers spoke very positively about a new health clinic in the community in the city, open 24 hours a day, where they could go to receive services related to both their physical and mental health problems. The fact that the clinic had trained mental health workers on staff was one particularly desirable aspect of this service.

Consumers were enthusiastic about programs that were offered in the community instead of in a mental institution or acute care facility. As one consumer mentioned: "I attend two agencies and between them they also offer crisis services and crisis stabilization. It's good as it prevents being hospitalized."

One aspect of many mental disorders is the cyclical nature. Consumers are at times doing very well and their condition is stabilized while at other times they decompensate, which can occur gradually or rapidly. Consequently, participants liked programs that offered support at a level related to their needs.

For example, programs where there was a gradual transition from hospital, with an intensive level of service, to community where one was required to be more independent were viewed favourably by clients. One consumer regarded a homemaker

service in a very complimentary light because: “Instead of taking me from a secure environment in the hospital and throwing me right back into the fold, it was a gradual easing back into the fold...I did have it (the service) and it worked.”

One respondent at an agency liked the freedom that was allowed there. He remarked: “You can do what you want, go where you want and talk about things. If you don’t want to talk to somebody, you just move to the next table. They also have some rules that are helpful. If they (the consumers) want to be abusive, controlling, or obnoxious...you’re banned for a few months.”

In contrast to the flexibility mentioned above, respondents experienced frustration with programs that they perceived as inflexible. Some consumers resented the requirement that they must have goals to work on and that those goals had to be completed in a specific time period. One consumers’ remarks capture those noted by others: “You have to be focused on a goal and they make you literally sign a piece of paper stating, write down a bunch of goals that you want to achieve in a certain amount of time...but it depends on the person and the illness that they have as to how long it will take to achieve the goal.”

Another who had been seeing a counsellor for quite some time and found her sessions with her very valuable, was increasingly frustrated when the mandate of the program changed and she was dropped from the worker’s caseload. With considerable effort the consumer eventually received special permission to still see this counsellor, but the sessions were reduced from once per week to once per month.

A third consumer’s remarks mirrored a problem identified by many regarding having to change the professionals one was involved with when one changed agencies.

She said: “My therapist was good but once you get a psychiatrist here, a therapist is a pre-requisite so I had to drop my therapist at the other place.” Another talked about the inflexibility shown by the agency where she was receiving services. She said: “There was no flexibility and too much responsibility on the client. I needed more structure and I didn’t like the atmosphere.”

A fourth respondent was very angry that because she was on social assistance, other agencies would not help her with her other needs. She said: “I’m not allowed to get a lot of the additional services because I’m on welfare...Everybody’s comment is, well you’re being taken care of. Well that’s not true and it not even for me, it’s for my son. I can’t better my son’s life because I’m caught between a rock and hard place. I can’t go out and work so I can never increase my income. Penny for penny they take everything.”

Often consumers were involved at an agency where they utilized several programs. Consumers were pleased to have a variety of program options open to them, particularly if the programs were significantly different. For example, consumers who needed a therapeutic program also liked being involved in programs at the same agency that were more social in nature or less intense. One consumer put it this way: “I’m involved in the Comfort Group, Life Skills Group and a Writing Course here. I consider it (the Writing Course) my playtime because sometimes Life Skills gets really intense.” For another, the variety of less intense programs, which were seen as non-traditional, was viewed very positively. One woman stated: “I’m involved in the art, composition and writing programs. It’s great mental stimulation.” Another consumer commented:

There really isn't that many centres like this in Calgary...somewhere where you can come and there's structured activities and you can sit around and socialize with people and there's a support base there because all the workers have access to your files so if your worker isn't available, at least there is someone that has an idea of your case and you can talk to them.

Another respondent was excited about the various program options open to her: "There's cooking classes, we did a play, we went to William Watson Lodge, there's pottery, the Internet, assertiveness training and parenting classes.

Similarly, consumers also regarded positively, those agencies that offered some type of meals, bathing facilities and recreation programs along with their mainstay services. One informant appreciated the opportunity to be with other people and said: "I got to meet people there and got involved in groups and activities." Another consumer's remarks summed up those noted by many: "It (the agency) was great. There were evening activities, movies, bingo, meetings and meals." Another found these types of agencies a lifeline for him as they offered: "Showers, two free meals a day and you can get clothes there."

Programs that taught consumers or helped them to develop certain skills were desirable. As one consumer stated: "The group approach was supportive. It helped me to learn to cope and learn skills."

Various consumers indicated they liked programs where it was recognized or acknowledged that consumers were often functioning at different levels and had different needs. One consumer who engaged in hours of therapy felt positive about the therapy she was receiving. Her comment was that: "It is more in-depth." Another consumer's

comments were reflective of those spoken by many: “(They) need differentiated services. Some clients are too sick and I don’t want to be around them. I find it really stressful sometimes interacting with some of the lower functioning people. Like their battiness almost drives me batty.”

Consumers experienced difficulty with programs where they were not informed about the program or entitlements. One woman’s experience mirrored those of other consumers: “The social services policy is if they (clients) don’t ask, don’t tell. And if they ask and you say no and they don’t push it, then that’s fine too. So you learn from what other people may have received and how they went about and got it.”

Factors Related to the Staff

Participants identified a number of themes that focused specifically on the staff involved in offering supports to them. An analysis of these themes pointed out that certain qualities that staff possessed, such as showing care and concern were important for the consumers. Staff who were skilled in dealing with a range of consumers and consumer behaviours, staff who were knowledgeable and experienced, and consistent staff who stayed working in a program area all were viewed as contributing positively to the consumers’ experiences in a program.

Staff Qualities

A major factor that made a real difference to consumers as to whether they were satisfied with a program or service related to the qualities displayed by the staff working their. These are identified below.

Participants identified as important, a set of qualities possessed by staff that were related to demonstrations of support, caring, hope, sensitivity, warmth, validation and

non-judgmental attitudes. They indicated that these staff qualities were nearly essential for them to enter and stay involved in a program. Others remarked that workers were helpful when they were optimistic about a consumer's future. As one said: "She (the worker) believes in her clients and she wants the best for them and she does things to help them." Another said: "He (the group facilitator) tell us how far we've come along."

One consumer really liked a life skills program she was engaged in because: "The staff were good and they were not controlling." Others spoke positively regarding workers who made time for them. As one consumer put it: "I had a great worker who was supportive. Through all that time, I had the comfort of knowing that if I really needed someone to talk to that (the staff) was there...she would make time for me. That was really comforting." A number of consumers talked encouragingly about their workers because they were non-judgmental, accepting, gentle, patient, wonderful, warm, affirming, encouraging and supportive. As one remarked: "It was really good and non-judgmental and I made friends. It's been really good for me because I learned that I can trust people in there and its become a safe place. And I can say anything and I won't be judged and they'll help me out if I'm in a bad mood, sad or whatever."

Consumers were grateful to their workers when their experiences were validated. A number of participants finally had a worker who accepted as true, their experience of abuse. As she exclaimed: "My abuse was believed. I got a new perspective and I was believed."

Other participants had negative experiences with the staff. One individual, who developed mental health problems, was a trained professional in the field before becoming ill herself and her observations from working in the field were quite different.

Commenting on the same subject as the consumers above, she exclaimed: “In the real working world it’s very cold and competitive. The health care workers that I worked along side with would basically punch the clock, not treating the consumers well.”

Another respondent found staff was often very insensitive. She believed she had to fight for everything in terms of receiving services and stated: “There were times when they (workers) haven’t taken my call and there were times when the workers didn’t return my calls.” This same consumer remarked:

Once when I was in the hospital they took my homemaker out of my home and left my 8 years old son alone...They left him there unattended...I said excuse me, if I was at home and went out and didn’t come home overnight and left my son alone, you would have attacked me for being a neglectful mother and taken my child away yet here I am trying to get medical treatment and you’re taking my support away from my son...I don’t find them (social services) supportive. I find them almost adversarial...and they have control over you life.

A number of research participants experienced abuse at the hands of the professionals and caregivers who were supposedly working to help them. One woman described an ordeal at the emergency unit of a hospital where she had gone for help after slashing her wrists. She exclaimed: “I’ve had some really bad experiences where I’ve been sutured without anesthetic, simply because the resident said, well, I’m going to teach you a lesson so you never cut again and she sutured me without anesthetic. I’ve had incidences where I’ve been treated for overdoses that weren’t overdoses, where you go through the activated charcoal and the whole bit.”

Another participant was abused by other consumers in the program and notified the staff who did not intervene and the abuse continued. One participant who was abused by other consumers said this: “I was being physically and verbally abused by other clients in the residential program...and the manager didn’t help.” This same consumer already possessed a history of sexual abuse and that was why she was receiving services at this agency in the first place. Another consumer, in the same program, echoed the first consumer’s remarks:

There was a lot of yelling and verbal abuse (by other consumers of the program). She tried to smash my back door in, once. She lived right across the hall from me. I did not feel comfortable being there...other tenants were abusing me and the management wasn’t doing anything to stop it. And the woman who lived underneath me, she literally had a physical fist fight with another tenant and that’s grounds for eviction but they did not evict her. So she ran terror over everybody in the Centre.

The ability of the worker to listen well was an important variable for consumers as to how they felt about a program. Consumers consistently were positive about their relationship with their worker and found their worker to be helpful to them when the worker listened well. Reflecting remarks made by numerous consumers, one said: “She (the worker) listens actually and she’s really good at listening. And I needed somebody who would listen to me.”

A number of consumers, particularly those involved in counselling, found their counsellor did not listen well and also told the consumer what to do. All consumers who had these experiences ended up disliking their counsellor. As one exclaimed about her

therapist: “She doesn’t listen to me and she tells me what to do. It’s hard to listen to her sometimes because she’s always right about things!”

A number of participants identified controlling behaviour on the part of staff as particularly problematic for them. What was really important was being involved with staff who were not controlling or domineering and where the consumer felt he/she had some autonomy and control. One consumer observed this about her therapist: “I sometimes get that feeling like he’s not empathizing as much as maybe he should be. He’s just like a preacher, he sermonizes.” Another respondent exclaimed: “This person (the therapist) would just lecture at me instead of allowing me to proceed at my own time.”

It was not uncommon for respondents to be involved with an individual staff member and then be assigned a new staff person. How this change was dealt with by the staff impacted the consumer either positively or negatively. Many participants had worked with a number of different staff during the course of receiving services. Often this transition was handled poorly.

For example, one consumer expressed frustration with her worker’s insensitivity when she transferred to another program leaving the consumer to connect with a new worker: “I guess you could say I learned a lesson this weekend. They are there to do their job and that’s it. A professional has a job, they do the job and that’s it. Don’t get close, don’t touch, don’t think, don’t feel.” Another said this when she discovered her recently assigned worker was changing programs and she would now have a new worker: “Again same story, no termination, no goodbye, no good luck.”

Consumers wanted to have workers who were reliable; that is they wanted workers that they could count on them. They resented workers who were irresponsible in their commitments to the consumer. For example, one consumer related: “She (the worker) would show up late and she would not phone.” Another commented on the worker at a homemaker service she had used in the past: “She came late, left early and didn’t clean. She would watch t.v. and put in her time sheet for the full hours.”

The Staff's Skills in Dealing with a Range of Consumers and Consumer Behaviour

Consumers found they were more satisfied with programs and services when the staff working in the programs possessed a high degree of tolerance, displayed flexibility and demonstrated the ability to work with diverse consumers and diverse needs.

One consumer exclaimed how appreciative she was of the worker who ran her group: “(The staff) has always been very understanding and tolerant. I’ve missed a lot of classes and I’ve been chronically late and she keeps giving me chances.” Another exclaimed about his group leader: “He praises you when he thinks you need it...He’s just an excellent facilitator.”

Some consumers identified having problems with workers when the consumer contacted them frequently. For example, in Calgary there is a crisis line and a number of consumers thought the workers staffing the phone lines often became frustrated with the consumer if he/she called the line often. As one said: “They got tired of me” and this was difficult for her.

Others felt angry and discouraged by workers who were insensitive about a consumer’s situation. One respondent tearfully described her experience:

They gave me the information package and the options and it was helpful but one worker didn't take into account I was sick and she kept cutting me off. I wasn't putting my cards in at proper times and she was closing my file on me all the time and that was adding stress. You know the way some of them (social workers) talk to you, rudely...it's like I was afraid to even phone them...Put you down like you're doggy doo...Well it's always the same thing. If you can't afford the house, move. Well that's easier said than done...Go into shared accommodations, find a cheaper apartment. Where? Where do you find a cheaper apartment?...Am I supposed to move in with a complete stranger just because you're saying I have to?...I got frustrated, depressed and stressed.

Commenting on the same subject, a consumer exclaimed:

Cause in social services you're guilty and you have to prove you innocent. At any given moment they could just cut you off, and they don't even give any warning, they don't even call and say we're cutting you off because of this or you need to deal with this or you will be cut off. You just don't get a cheque. And you've got rent to pay and you don't have a cheque in your bank account and you don't know why. And then you have to phone them and wait for them to decide to get back. So it leaves you in limbo and in a state of constant fear at the end of the month until you get that cheque in your account and you feel very out of control.

One consumer experienced trouble with her worker. She said: "She didn't give you the time that you needed. I felt that I was an imposition. I felt she was doing, she thought she was doing me a big favour (by seeing me). Well, I was doing her a big favour being sick. Without me being sick, she wouldn't have a job."

The Staff's Knowledge and Experience

Consumers were impressed with workers when they demonstrated a good knowledge base of the mental health field, a good knowledge of the community and appropriate resources, and when they knew how to access other services and resources. One consumer found it very helpful “when the staff helped me with some referrals.” Another became frustrated, though, when she needed help gaining employment and “her psychiatrist didn’t refer her to an employment agency until much later.”

Consumers were pleased when their workers were knowledgeable about advocacy, particularly advocacy on an individual level. Often they required someone to advocate on their behalf in terms of dealing with parts of the system and they wanted workers who knew how to do this effectively. As one consumer said:

You’re assigned a worker and they often act as an advocate for you between social services. She’s been a great buffer between me and social services because I do not do well with social services when I get talked down to...I withdraw and I don’t say what I should or I don’t assert myself the way I should...The workers are great advocates for you...and give you different options.

Consumers were more satisfied with programs and services when they thought the worker(s) was experienced, well trained and knew what they were doing. One consumer felt favourable about a group where she had confidence in its leaders. She said: “There were more skilled leaders...The group facilitators gave me the opportunity to speak for myself...the facilitators were more skilled.” For another, she spoke in complimentary terms about her psychologist whom she had worked with for over two years. She remarked: “My therapist has had some of my experiences and he understands working

with street people. He's easygoing and he's laid back and he's an older gentleman and it's a lot easier for me (to work with him) instead of some snot-nosed little kid trying to tell me what to do."

Research participants spoke of the difficulty in being involved in a program when the worker did not seem to know what they were doing or did not have knowledge in a certain area. One respondent spoke about a group leader who was a student and how inexperienced she was. The agency did not have a more skilled leader in the room to assist the student. Another consumer said this about the group leader: "(He) wasn't strong and he kept losing control of the group." One participant talked about a group leader running a group when she did not have any knowledge about the consumer's mental illness, multiple personality disorder (M.P.D) or how to conduct a group. The consumer was very unhappy with the group and stated: "First there was the stigma of M.P.D. Then the group leader was inexperienced and didn't do it (begin the group) well. (In) this last group they just described what our disorder was and (that) spooked most of the people. So then I had to deal with the stigma."

One consumer felt the service she was receiving to help her deal with abuse by her daughter was inadequate. She said: "They (the agency) helped me with stress management but no one told me to lay charges."

Staff Consistency (Turnover)

Whether consumers consistently had the same staff when involved in a service or program was important. One consumer spoke positively about the fact that the professionals in her life had remained quite consistent over the years. However, most

consumers identified having to deal with many different workers and how frustrating this change was for them. Illustrative examples of consumers' comments were these: "I've been involved with a lot of different workers and it's too much." One consumer remarked: "She (the worker) worked with me just over a month and then she said to me, well, I have to move (to work in a different program)."

Interacting with the Medical Community - The Physicians

All consumers interviewed previously or currently were seeing a physician about their mental health. While it is often thought that the medication doctors prescribe to treat mental illness is the most important service they can offer, consumers had something different to say. These factors are presented in Table 5.2.

Table 5.2
<u>Physician Factors Important to Consumers</u>
The Factors
Physician's relational skills
Physicians confidence in a future for the consumer
Trust that the physicians will use their power appropriately
Accessible physicians
Knowledgeable physicians
Appropriate medication support by physicians

A Physician's Relational Skills

For most consumers, their doctor's attitude and relationship with them was paramount in their recovery process. When the doctor was negative or perceived as less

than caring, consumers were consistently dissatisfied with their doctors' services and often quit seeing their doctor.

Consumers were generally satisfied with their physician's treatment when they showed and/or developed an attitude of trust and concern. As one consumer said: "He was really good as he trusted me." Another said: "He was wonderful, sensitive, trusting and understanding."

Consumers liked doctors who listened, gave good advice or allowed them to make their own decisions. One consumer's experience reflected that of a number of consumers who were satisfied with their doctor:

He (the psychiatrist) has some ideas and he puts them out there and you can think about that...He listens to what I say and he describes his advice. Like if he says I should do something another way, he'll give me a reason why. And he's very open to different things. Through his questioning they discovered that I have thyroid problems. He just treated me like I was a human being. Like the other ones treated the depression only.

Consumers were dissatisfied with doctors that they perceived as directive or authoritarian. As one exasperated consumer stated: "My doctor is not going to change his mind. He directs the thing (the treatment), not me." It was not uncommon for consumers to identify their doctors' problematic attitude and behaviour as something that interfered in their treatment. One consumer described her doctor this way: "She's yelling at me from the top of her voice. I told her, don't talk to me that way. But she used to get mad all the time. So I found someone else."

Another said:

(My psychiatrist) was cold and unfeeling and it just didn't work out. What happened to end that relationship is I described this really horrible memory from childhood and he was saying you really shouldn't be focusing on that kind of thing. You should be focusing on finding a job, in a cold and unemotional tone, where I didn't feel that I had been heard or sympathy or support or anything like that...I wrote him a letter saying that I thought that it was abusive and that I didn't appreciate it. I still had made an appointment with...and he said...I read your little love letter that you left last time...that was jarring...(and) basically the rest of that session was a blur."

For a third, his family doctor treated him poorly because he had mental health problems. He stated: "My personal doctor doesn't listen to me because I have mental problems. (I feel) dismissed and ignored because he thinks it's a figment of my imagination. And I'm saying listen, when it comes to my body, I know what's wrong."

Treatment Expectations From a Physician

Consumers liked physicians when they possessed confidence in the consumer and displayed hopefulness regarding the consumer's future. As one consumer explained: "She's a very good psychiatrist. She does have expectations of me, which helps. She wants to see me going to Self Help, she wants to see me taking my medication. She wants to see that I recognize the signs of hypomania and depression and reach out for the help that I can reach out for."

The Power of the Physician

A number of consumers related feeling fearful of their doctor because of their power over the consumer related to involuntary committal or certain treatments. This

fear interfered with their relationship with their physician and with their treatment as well. One consumer explained it this way: “I’ve never told her (the psychiatrist) that I get delusional and hallucinated at times because I was afraid of being committed.”

Physician Accessibility

In Calgary, accessing the services of a physician related to an individual’s mental health was often problematic. Consumers continually complained about not being able to obtain an appointment with a physician, having to wait for an appointment, or not having a long enough appointment. One consumer who waited for an appointment when he needed to be seen immediately was told this by the doctor’s receptionist: “He is just jammed to the rafters. There’s nothing, absolutely nothing, not even on a Saturday.” Another had to wait eight months to gain an appointment with her current psychiatrist. A number of consumers felt their psychiatrists were too busy to make any time for them at an appointment. What one woman said was: “I feel like I’m intruding.” Another said: “My appointments are too short, about 10 minutes.”

Consumers spoke positively about their doctors when they could call them and talk to them when they felt they needed to. Some doctors either encouraged this or were very open to it while others were not. As one consumer said: “He was so good as I could call him daily if I needed to.”

A frequent criticism related to accessing psychiatrists focused on Calgary’s current system in which psychiatrists had privileges at one hospital and/or served patients from one location of the city. That is, many psychiatrists were associated with a specific hospital and hospital program. If the consumer was discharged from hospital or did not attend the hospital’s program, and/or moved to another part of the city, they no longer

could utilize the original psychiatrist that they had been involved with. This was distressing to consumers, who often felt they had developed a relationship with their psychiatrist, their treatment was going well and they had no desire to have to find a new psychiatrist and start all over again. One consumer's comments mirrored those identified by many: "I've had many (psychiatrists) and everytime I've moved to a different program or part of the city I've had to change psychiatrist. It's very hard to tell your story again and open up to a new psychiatrist. One just read my file while I was in her office and then didn't listen."

Other consumers talked about having to see their doctor at a hospital even though the doctor had a clinic in the community that was closer to where these consumers lived. This inconvenienced consumers, particularly because they lacked transportation or the money to use transportation. Rarely were consumers attending medical clinics in their own communities but for those who were, this was where and how they wanted to receive their medical services.

For one consumer, having to see her doctor at the hospital was related to the lack of continuity regarding information in her file. As she mentioned, unhappily: "He's (the psychiatrist) got his notes in his office and they've (the hospital staff) got a different set of notes they are working off of at the hospital...(He says) so we know what's going on, we're going to have the same set of notes, so you're going to come to the hospital."

Others described the inflexibility of the mental health system that caused access problems for them with a doctor. For example, some agencies in the system required that one have both a therapist and a psychiatrist. At times consumers did not want both, and just wanted to see the psychiatrist only. Related to this concern was having to wait for

psychiatric service because a therapist was not available to take on a new consumer coming to the agency. Until the requirement of having both a psychiatrist and therapist was met, the consumer was not seen.

A Physician's Knowledge Base

Consumers were most satisfied with doctors who were knowledgeable, not only about the treatment of mental illness, but also about related issues that impacted their mental health and who communicated this knowledge base in an understandable way to the consumer. Consumers often experienced trouble getting information from their doctor about their mental illness and its treatment. As one consumer explained: "He (the doctor) told my mother my diagnosis and gave my mom the information but not me."

Some identified having difficulty with their doctor because of their doctor's lack of knowledge in certain areas. For example, one consumer was sexually abused and was being seen by a psychiatrist who was brought up in a different country and culture. Consequently, with the cultural differences present, the doctor did not recognize or view this consumer's history of sexual abuse as cause for concern. When the consumer pressed her for some assistance with her sexual abuse, the psychiatrist terminated the relationship. Her doctor did not believe another consumer, who had been physically abused by her husband, because he lacked knowledge about family violence. She remarked: "I couldn't get help from him because he didn't believe the way my husband was. He has this idea that all men are nice and loving."

For another, his psychiatrist's lack of knowledge about therapeutic interventions caused the consumer to quit attending his appointments. He described the experience like this: "I've gone through a few shrinks...I think they're just taking the Government for

their money...Like Dr.____, he just sat there and rocked in his chair and said and how does that make you feel? And I'd say one word and then we'd sit there for 10 seconds watching him rock. He never gave any good questions...for me. And it was horrible so I just pfft" (left).

Medication Support by a Physician

Most consumers had been or were taking medication for their mental illness with varying degrees of success. Consumers usually recognized the importance of medication in their treatment. What some took issue with, though, were physicians who treated their mental illness with medication only. Many consumers referred to them pejoratively as "pill pushers" who had no time for them and they viewed this negatively. One consumer noted: "Basically what it amounts to is I go to see him once a month...and he asks me how things are going...He just gives me a prescription for my medications and away I go and make another appointment." Another said: "She just gives me pills." A third stated: "It's go in, how are you doing, okay, bye bye. Or how are you doing, not too bad, okay we'll try this medication and then, bye. And...that's when it got to the point that I said, forget it."

However, for some consumers, recent changes to their medication resulting in them taking new medications on the market, was a more positive experience. They experienced good results with symptom control with few side effects. As one consumer in this situation said positively: "I'm on 4 different medications now. I seem to function more normally. I don't have episodes anymore. I rarely have seizures. I don't lose my temper as often and I don't get depressed anymore."

The most predominant theme related to taking medications for ones mental illness was the number of medications respondents had taken. Often there was period of trial and error when consumers were first introduced to medication(s). For consumers who had taken medication for a long period of time, frequently their medication was effective in reducing symptomatology for a time period and then it ceased to work. Then a different medication would be prescribed, with often the same result. Consumers described these patterns or cycles as extremely frustrating. As one consumer explained: “For those eight months it was like the flavour of the month.”

With the exception of consumers taking some of the new medications on the market, which to this point had few or no side effects, consumers uniformly complained about the various side effects associated with taking psychotropic medications. Front and centre were those of dryness of mouth, excessive thirst, and frequent urination. For some these side effects resulted in them deciding to not take their medication, which usually led to them becoming ill. Of concern to these individuals was how they were regarded by their physicians and service providers when this happened. A number felt they were negatively labeled as having compliance problems, terms which they felt were pejorative, and which did not take into account how distressing, unpleasant and disturbing to ones lifestyle some side effects were.

Consumers recognized the imprecision related to diagnosis and some consumers had been misdiagnosed. Thus they were placed on medication that was to reduce symptomatology for a specific mental illness, which they found out later they did not have, and the medication had had deleterious effects for the consumer. One consumer who was misdiagnosed with schizophrenia described her experience: “I was put on

medication for schizophrenia. They decided to put me on it as a trial. And it did weird things to me...the only reason they took me off it was because I was getting physical side effects.”

Issues in Specific Areas of Formal Support

From analyzing the respondent's data, consumers identified six other areas they regarded as constituting formal support: (1) financial support, (2) employment support, (3) transportation support, (4) leisure support, (5) educational support, and (6) legal support. In each of these areas, consumers discussed particular issues that they had to contend with.

Financial Support

Nearly all consumers interviewed were receiving some type of financial support from the government, usually the Assured Income for the Severely Handicapped (A.I.S.H.) or Social Assistance. One was receiving a Long Term Disability Pension from her former place of employment. For those on A.I.S.H., this fixed income amounted to \$823.00 per month plus medication and health benefits coverage. Nearly everyone described tremendous financial hardships. As one consumer on Social Assistance explained: “I had no money for 3 years. I had \$245.00 a month...and it came from social services. And so I couldn't afford a roof over my head. I owed 8 months rent at the last place I stayed at...(My Social Assistance) was \$245.00 and my rent was \$350.00.” However, for one consumer who now qualified for her Canada Pension, Old Age Pension and Supplement, for a total of \$1242.00 per month, she had this to say: “It left me feeling financially comfortable and feeling fine about my income.”

Table 5.3**Specific Areas of Formal Support****Types of Support**

Financial support
 Employment support
 Transportation support
 Leisure support
 Educational support
 Legal support

Some consumers receiving fixed incomes spoke of how little flexibility there was with their program. Amounts were typically fixed and did not take into account extenuating factors. One consumer was caught between two programs because she was unable to work yet had a child still living with her. She described having to contend with both her welfare benefit and her handicapped benefit programs which generated an income totaling \$1039.00 per month and that her benefits changed depending on whether her child lived with her or not.

Fixed incomes adjusted to family circumstances were an issue for other consumers. A consumer, who received A.I.S.H., was divorced and had his daughter with him on the weekends. He was not given any extra money to assist with caring for her on these weekends. As he said: "I was on welfare and now I'm on A.I.S.H. There are no allowances made for my having my daughter on weekends. It's a very, very tight budget to live on. It's very hard."

For another, she needed to obtain a divorce to obtain some of her assets and access to her children. However, with being on a fixed income, she had no money to hire a lawyer.

Others spoke of having major financial difficulties when they became ill which impacted them currently and made them worry about the future. For some they incurred extra expenses when they were ill, when they made poor judgement calls. As one consumer explained: "I'm on A.I.S.H. now and it's very tight because when I was sick I charged bills on Visa and now I can't pay it. This has given me a poor credit rating which could impact me getting a student loan and getting back to university." Others often lost their place of residence when they became too ill to handle their affairs. One man's experience typifies those of a number of others: "And last year (when I got sick) I went to hospital...I had no money in the bank, no assets, everything was gone and I only had the clothes on my back."

Consumers on fixed incomes had extra costs that were not covered and this was a particular hardship for them. With these extra expenses, some consumers talked about using their food money to pay their bills and using soup kitchens, always, as their only way to have food. As one consumer clarified: "It's very hard on A.I.S.H. particularly with extra expenses...moving, hook-up for utilities, cabs to get groceries etc." Regarding medication, there was a charge of \$2.00 per prescription up to \$6.00 per month that consumers had to pay. One respondent explained it like this: "On A.I.S.H it's very tight. You have to pay \$6.00 for prescriptions. You have to fork out \$6.00 every month for your drugs, for the first three prescriptions and then you only get a 30 day supply (so one

incurs this fee every month).” Others spoke of ambulance fees not being covered and at times they had had to call an ambulance and had been billed for this.

Those receiving A.I.S.H. were entitled to earn up to \$165.00 per month, without their A.I.S.H. benefits being reduced. However, nearly all consumers interviewed had no paid employment to top up their monthly income. Those on social assistance received considerably less money. For consumers with these two sources of income, poverty and hardship typified their situation. As well there was a sense of hopelessness as to their situation ever changing and as one noted: “With a fixed income you never can have anything extra.”

Consumers spoke of the disincentives associated with working as any income earned would be deleted off their cheque. One woman had worked while on A.I.S.H. and had earned \$300.00 per month, well over the \$165.00 extra allowed on A.I.S.H. This is what she said: “ I was on A.I.S.H at the time...and then of course when A.I.S.H. found out I was working they said, oh, that’s good, so I would get a cheque of \$300.00 and they would help themselves to \$300.00 off my cheque...so then I thought, great. I make \$300.00, and they take \$300.00.”

A few research participants had their bus pass paid for them which was extremely helpful. Usually special circumstances were required for a consumer to be eligible for a paid bus pass yet these were unclear. For example, one consumer receiving social assistance was given money for her bus pass, but only while she was taking a course. She said: “Right now during Life Skills, my...worker considers bus passes an employment expense, so they’re paying for it but as of the August cheque it won’t be paid for anymore because Life Skills ends.” Another consumer felt both relieved and angry when she was

approved for a subsidized bus pass after waiting for 5 years. Her concern related to how she qualified for the bus pass. She exclaimed:

She (the worker) asked me what some of the difficulties were and I said well one of the greatest problems is the expense of bus fare...Bus passes are \$48.00 per month and that's a huge tax on my income...So she wrote a letter to my financial worker and requested that she supported me coming down (here) and that the programs that they offer here are needed for my mental health and my well-being...And yesterday I received a letter...that an additional \$48.00 has been included in my monthly income...It's not what your needs are but who you can get to ask for them...somebody was in my corner that had enough power to find a loophole.

One consumer was on A.I.S.H. and used part of her income to pay for a bus pass. She said: "Money is very tight but I buy my own bus pass as that's very important."

The only consumer to have a disability pension through her former employer also found living on a fixed income quite grim. She remarked: "I own a vehicle and repairs are expensive. I have no money for leisure but I'm able to make my basic payments a month. It's just that I don't have a lot left over. Like I can't go out to the movies or do much shopping. My parents had to help pay for my vehicle repairs.

Some respondents on fixed incomes shared the cost of an apartment with another in order to cover their costs. Those with a subsidized apartment were a little better off financially and sometimes had a place of their own. Some consumers, who were on A.I.S.H. and had obtained subsidized housing were able to make ends meet. As one said: "A.I.S.H is no problem with my subsidized apartment."

Nearly all the consumers on a fixed income experienced difficulty budgeting with the income they did receive. For many their income was meager. Relative to their monthly expenses, even with budgeting skills, consumers had so little money to work with that it did not meet their most basic expenses. Consumers often did not have the necessary budgeting skills to handle their money and could not make it last over a month period of time. One consumer's experience illustrates those of many others: "Welfare had been set up for me. I didn't know how to handle my money and I had spent all my food money by the 12th of the month." Another on social assistance had \$100.00 left over after he had paid his group home rent for the first time. What happened was this: "I'm out of money and it's only July 10. And I have no money for a bus pass...and I'm now out of tickets and I still have lots of appointments this month." This same consumer also had no money left this month for food. A number of consumers in this situation paid their rent and went without buying food.

The consumers who lived in group homes and had difficulty budgeting their money relied on the staff to handle their money for them. Whether staff had Trusteeship was not clear but it seemed that in these cases, this arrangement was more informal than formal. One consumer, who found living on A.I.S.H difficult stated: "Now the staff (at her group home) save my money for me." Only one respondent interviewed actually saved money on A.I.S.H. He did this by: "Living in a terrible hotel room, living very frugally and getting free meals always."

Respondents' experiences were mixed as to their success in accessing A.I.S.H. both for the first time and as well, if they had had to reapply. One consumer resented that: "You must apply for all other benefits to be eligible." Another consumer who had

applied for A.I.S.H. said: “I had no problem qualifying.” One more participant who had re-applied for A.I.S.H. said this: “I had no problem getting back on A.I.S.H.” A fourth who was currently receiving Social Assistance applied for A.I.S.H. but after three months, had not heard on the status of his application. Another consumer echoed those remarks by saying: “I’ve applied for A.I.S.H and I’ve been waiting about 4 months. I’m destitute. I’m on Social Assistance now (\$229.00) and I’m very poor. I have no money for food. I eat at agencies and get handouts.”

At the time of her interview, this consumer did not know where her next meal was coming from. She described her situation graphically:

If I’m lucky, maybe I’ll mooch something upstairs (at the agency where she was attending a program) or I’ll go home. Last night they had some guy come in from the food bank with some bread and stuff and that’s what I’ve been living on for the last few days. It’s like I butter up a couple of slices of bread and that’s my meal. I have to also pay storage fees for my furniture (as her subsidized place is furnished and her things won’t fit in there) and my bus pass.”

Some consumers interviewed had, at certain times in their lives been without any income. As one consumer said who lived for a period of time on the streets: “I sold drugs to make ends meet.”

Employment Support

While many Calgarians who want to work have employment, this experience is not shared by people who have a mental illness. Of all the consumers interviewed for this research project, none currently were in paid employment in the workforce. Yet, most had worked in the past, some for long periods of time. A commonality, though, was that

nearly all consumers had lost their jobs when they were mentally ill and unable to carry out the functions of the job. One woman's experience illustrates this point. She was an educated childcare worker who had post-traumatic stress disorder. She said: "The problem was I couldn't focus because, can you imagine having flashbacks to your traumatic childhood, and trying to take care of children at the same time."

Of note, was what consumers felt like when they had been working and had mental health problems. A number of respondents, while handling their job well, felt constantly anxious that they would be fired and they worried that their employer would discover their secret. One consumer actually quit her job for this reason. She said: "I always felt anxious. I was always afraid they were going to fire me so I quit. Yet in fact I had never been fired from a job." Others fretted over their work and thought their work had to be better than others in the organization because their employer knew they had a mental illness. This put undue stress on the consumer.

Another theme that emerged in the data was the sense of hopelessness many consumers held about ever returning to the workforce. Most believed their illness was such that they would not be able to function in the workplace or that they would not be given a chance by an employer to be hired into a job because of their illness. As one consumer responded emphatically when asked if she thought in the future she could return to work: "No, I couldn't handle it." Some had experienced stigma by employers. Others felt anxious about applying for jobs as they did not know how to explain gaps in their resume. While some consumers hoped to get involved in the workforce in the future, few actually thought that this would happen.

A number of consumers talked about the difficulties associated with being underemployed or unemployed. One consumer who had participated in two employment programs said: "The work was limited. I had mindless jobs when I'm actually quite intelligent."

Along with this, many spoke about how work gave them a sense of identity, a feeling that they were contributing to society, and a much needed income. With them not working, or them working in a job that was below their level of skill and ability, these disappeared. As one consumer explained: "When I lost my job, I ended up again feeling useless, helpless and hopeless. I ended up feeling like everything was my fault. I was depressed and I ended up in hospital...I couldn't cope with that loss." Another consumer, who worked as a surveyor for many years, and earned a good income, mentioned how: "Returning to work is imperative for me so that I can again earn a decent income." A third stated: "When I lost my job it was very devastating...I got more depressed, couldn't find another job and I gained weight."

When consumers were working and let go from the job because of their mental health problems, their experiences varied as to how the organization or business handled this. One woman, who was now receiving a long-term disability pension from her former employer, was treated very well when she became too ill to work. She said: "They (the company) was good and I got a referral to the outpatient clinic at the hospital and to a community agency."

For some others, their situation was not handled sensitively and rarely were accommodations made at the workplace before dismissal occurred. As one woman described:

I was still working and seeing a psychiatrist because of depression and she wanted to work with me in the sense of having one day a month that I would take off from work and go see her...They (the employer) insisted on knowing why. I told them that I was dealing with depression and they started to demote me, feeling I wasn't suitable, coming up with something concerning my paperwork...coming up with a lot of different reasons why I just wasn't a team player or something and I figured out that I wasn't coping, they weren't coping with me and my psychiatrist just felt it was in my best interest to quit the job. There were no accommodations made. At my workplace that just didn't happen.

For another, who had schizophrenia and was a licensed practical nurse for 11 years, not only were no accommodations made for him, but as well the length of his workday increased from 8 hours a day to 12 hours a day, making it prohibitive for him to continue to work. As he explained: 'I was diagnosed in 1989 with schizophrenia...and it was getting progressively worse...Some fine person somewhere decided how about we can make them work 12 hours days, 3 days per week and then they can have more days off. But the problem with that is that it makes you that much more tired because you are there that much longer. So that when you do have time off, you need that much longer to recover...I was so exhausted.'

Sometimes consumers experienced side effects related to their medication, which interfered with their ability to do their work. One consumer's familiarity with this was graphically illustrated when he told his story. He remarked:

And then I tried Home Care (as his job). And the problem with that, with my mouth being as dry as it is, you have to drink so much water. Going to the

washroom is a problem because you can't go when it's convenient. Sometimes you're on the bus (going to their home)...and it was so inconvenient that I would wet myself or I'd get to the place and before saying hello, you'd knock on the door, they'd say come in...and you'd have to run to their kitchen and grab a glass of water and drink it because you couldn't talk.

Many consumers spoke of the lack of assistance available to them regarding returning to the workplace. While some agencies existed in Calgary to help people with a job search, resume writing and managing a job interview, little help was available to work with employers so they would hire consumers or to assist consumers with on-site job coaching.

A number of consumers talked about the difficulty of finding paid employment because of their lack of education. As one consumer with Grade 6 education stated: "I've changed jobs often to try and make more money and I would like to return to work. But I'm not well right now and I have such limited education."

Some respondents explained how, because of their poor living circumstances, finding employment was very hard. One woman exclaimed: "Its very hard to work with no roof over your head or no permanent or stable housing."

Numerous consumers were doing volunteer work either as something to do to fill their time or as a way to develop their work habits and job skills. Consumers had mixed responses about volunteering. One consumer was very negative about volunteering: "I've got my parents saying I should do volunteer work but when you do volunteer work, that means freebies...and everybody loves a freebie. Well, I'm freebied out, sorry guys. I don't do freebies anymore because I've learned my lesson. People take advantage of

freebies.” However, another consumer had a different experience, liked volunteering and felt this was all she could handle right now. She commented: “I’m not ready (to work) right now but I like volunteering. I’d like to get back to work but...I have a bad tendency...If I go anywhere strange, I start shaking. I’m doing volunteer work and sometimes even the 3 hours a day is really hard to get through.”

Transportation Support

A number of issues emerged related to the transportation area for consumers. The majority of consumers had transportation concerns.

A few respondents accessed the Handi-bus to get around the city. Respondents had varied experiences with this mode of transportation. Using the Handi-bus to attend regular commitments or appointments worked well. In these instances, because one could book the Handi-bus ahead of time, the transportation was reliable and prompt. However, in those situations where ones outings were more spontaneous, the use of the Handi-bus was problematic. Essentially, this service had difficulty responding to a request for pick-up unless the booking was made well in advance. One of the reasons identified by consumers for this had to do with a shortage of buses. Consequently, consumers using this service had to plan every trip ahead of time and this was extremely frustrating to them. As one respondent exclaimed: “You have to be really organized so if I want to go (for a casual outing), you can’t do anything spontaneously.”

A few consumers did have a driver’s license but only one respondent interviewed owned a vehicle. This also was the only respondent whose source of income was a work related disability pension, which meant her income, was higher than consumers receiving A.I.S.H. or Social Assistance. Consumers who did drive cited the cost of purchasing and

maintaining a vehicle as the primary reasons why they did not own a vehicle. Even for the consumer who did drive her own vehicle, she relied on her parents to assist her with vehicle repairs. However, she was very pleased to be able to drive. As she stated: "It's great to have a vehicle. I have more freedom of going somewhere whenever I wanted to."

Many consumers had no means of transportation because they could not afford to use public transportation while being on a fixed income. These consumers walked everywhere, which was less of a problem for those living in the downtown core, but still a problem nevertheless. Consumers were limited when grocery shopping as they could only carry small amounts of groceries when on foot. Some had appointments in other parts of the city (e.g., their psychiatrist's office) and they had no way of getting there. One consumer quit attending his medical appointments because of this. He said: "I walk most everywhere as I'm close to downtown but I need a bus to get to my G.P. (sic) but I can't afford it so I've missed a lot of appointments."

A few consumers used taxicabs to get around the city. Usually these consumers had special needs or circumstances that made this type of transportation necessary. One frequent example of a time when consumers used a taxicab for transportation was when they were experiencing a crisis or an acute episode and they needed to get to the hospital. However the cost associated with using taxicabs was prohibitive. One consumer explained it like this: "I had to take a cab to get to hospital when I was sick. I was on welfare and could not afford it."

While most consumers needed to use the public transit system, few did because of the cost of a bus pass. When consumers were on fixed incomes, there was no money left over to purchase a bus pass. Scarcely any consumers had a subsidized bus pass and

receipt of one of these was inconsistent. An eligibility criterion varied and consumers thought workers arbitrarily determined it. One consumer, who paid for her own bus pass, said this: "I buy a bus pass out of my welfare cheque but then I have no money for food." Another consumer qualified for a senior's bus pass that cost her \$15.00 a year. This was extremely helpful to her and she used the bus and C-Train extensively.

Leisure Supports

Consumers viewed engaging in leisure (recreation or social) activities an important dimension of their quality of life. However, most consumers found it difficult to participate in leisure activities for a variety of reasons and a few consumers stated they did not partake at all. An analysis of factors consumers had experienced related to leisure supports is presented in Table 5.4.

Table 5.4 <u>Issues Related to Leisure Supports</u>
The Issues
Cost of the leisure activity Location of the leisure activity A choice of leisure activities The time of the leisure activities The stigma of mental health agency leisure activities

A major factor that precluded consumers from engaging in social activities was that most activities had a cost associated with them. Consumers usually were receiving a fixed, limited income and so there was little to no money in their budget for leisure. A

female consumer said this: "It's a big problem as I have no money for leisure...(My) friends also have no money for leisure so I can't do anything."

For those who were involved in leisure activities, it was commonplace for these to be activities offered at an agency where they were receiving other services. Consumers cited two main reasons why they utilized leisure services at a mental health agency. Most activities at agencies were either free or had a very minimal cost associated with them. The second reason had to do with engaging in activities with people who also had mental health problems. Consumers felt they were more understood and accepted in these situations when they with people who also were mental health consumers.

In a very few instances, consumers participated in regular leisure activities in their home community and for these consumers this was very important. For example, one consumer belonged to the Lion's Club and took Tai Chi at a local club. Another took Jazzercise and Aquasize classes at the Y.W.C.A. These particular consumers wanted to engage in social activities that anyone would engage in and they did not want to participate in activities only where there were other mental health consumers.

When participating in activities offered by agencies, consumers spoke very positively about their experiences. One theme of note was the variety of activities offered. Many consumers believed they would not, on their own, be able to be involved in most of the activities offered by the agency. For example, some agencies took the consumers to Kananaskis, did pottery, offered cooking classes or opportunities to learn how to use a computer and go on the Internet.

The time(s) that activities were offered was particularly important. Consumers liked leisure activities that were offered on more than one day, during evenings and

weekends. This meant they could then access the activity at times that fit with their schedule and as well, have something to do on evenings and weekends when time was often heavy on their hands.

Education Supports

Although not a large number, some consumers had attended college or university. Respondents had various experiences with the post-secondary education system and its responsiveness to them.

The few consumers who had attended college or university believed that accommodations were made for them when they asked for them and these had been helpful in terms of them completing their courses. Accommodations related to having extensions on assignments, writing exams in a quiet place away from other students, or being allowed to miss an exam and later re-write it. For example, one consumer spoke of the instructor allowing her to have more time to write exams, because the student had difficulty concentrating. However, some consumers dropped out of the post-secondary system, because they were experiencing mental health problems and they could not cope. They were not aware of any help within the post-secondary system that would assist them with their studies and at the same time take into consideration that they were having mental health difficulties.

Consumers spoke of the difficulty accessing post-secondary education because the cost of college or university tuition was prohibitive, particularly when they were on limited or fixed incomes. In addition related costs associated with attending school precluded some consumers from attending. One respondent said this: "I want to take a journalism at S.A.I.T. and I'm taking a short course there now, but I can't afford the bus."

Legal Supports

A number of respondents indicated needing legal services. Consumers identified two major legal issues that impacted them negatively and which they required the services of lawyer to assist them.

One such issue involved consumers in conflict with the law when they had been mentally ill. During those times, they could not afford nor access a lawyer and sometimes they were found guilty of a criminal offence and were sentenced. They felt that when they were most vulnerable, and thus unable to handle their legal affairs competently, that they were charged, found guilty and sentenced inappropriately. One man described getting sick, ending up living on the streets, and stealing food to survive. He was subsequently charged and convicted and ended up on the forensic unit at a hospital. Although he has since been released, he is still on probation.

The second legal issue and area of need identified by the participants, related to the area of family law. Matters pertaining to legal separations, divorce, property settlements, child custody, child support and alimony were for most consumers, areas they could not pursue legally, as they did not have the money to retain a lawyer. Because these matters were often left unresolved, consumers experienced tremendous hardship by not having access to their children or their family home or by having to live in poverty.

Stigma

Stigma or the notion of being shamed, discredited or socially disabled because of the application of a certain label (Henshel, 1990; Spooner, 1998) was a concern raised by a variety of consumers. Mechanic (1999) indicates that the area of mental illness, particularly psychotic disorders, are more stigmatizing than other medical illnesses.

Additionally he mentions that this stigma makes it more difficult for the mentally disordered to be seen as individuals by the bureaucracy and professionals working in the system. A number of respondents experienced stigma associated with having a mental health problem and this stigma occurred in various ways.

Some participants indicated concern regarding the way their mental illness was depicted, both in the media and by professionals. One consumer who was involved in group therapy and felt stigmatized said this about the group leader: "She started out telling the group that I had M.P.D. (multiple personality disorder) and yet she didn't go into anyone else's illness. The group then didn't accept me as they were scared off by my diagnosis."

A number of respondents experienced stigma when involved in normal day-to-day activities. Areas identified were accessing housing, engaging in leisure activities and experiencing stigmatizing professional attitudes.

One consumer related what happened to her and a friend when they were staying at a hotel for a weekend:

We were talking about our illnesses when a lady overheard us say that my friend was at one time legally insane and she, (the lady) took it badly...She never said a word to us...but I heard them talking about us...They treated us like we...had some sort of terrible disease, that we should be shunned and they followed us up to our room...Later on I happened to go downstairs when the lady was down there. She was demanding to know why we were allowed in that hotel in the first place. She wanted to switch rooms with somebody. They wanted their money back and they weren't given their money back. And they threatened to call a lawyer. It was a

really bad scene and she turned around and saw me. She never said a word to me...It just sort of ruined everything.

Another felt stigmatized by his family physician. When he visited him about his general health problems, his doctor did not listen to him and thus his physical complaints were not adequately addressed. His experience was like this: "My G.P. won't listen to me and he dismisses me because I have mental health problems."

Consumers also spoke about the stigma associated with involvement in certain programs. One consumer who previously resided in a group home, lived on her own and was now being encouraged by her workers to return to living in a group home. She remarked: "There's a real stigma related to moving back into a group home as only really sick people who are not doing well live there."

It was common to be the recipient of stigma when accessing housing. For example, often landlords, if they found out a consumer was on a fixed income or had mental health problems, were not welcoming to consumers as prospective tenants. When consumers were already renting a unit, they sometimes found themselves the recipients of eviction notices or large rent increases, which they felt were related to the landlord wanting them out of the building. Two consumers, who lived together had this experience: "He (the landlord) wanted to evict us and he kept saying, your kind...I just want your fucking kind out of here." These same consumers went to various lengths to try to cover up the fact that they had a mental illness so that their neighbours in the apartment would not think less of them or treat them differently. They said: "(If we were) dealing with a crisis or you know a suicide attempt or something, we'd try to cover

that up and try to make it look like there was some other reason why the ambulance was called.”

The Informal Supports

Respondents identified needing informal supports, namely relationships in their lives. These were important in their mental health recovery. Relationships were divided into two types: (1) family and, (2) friends.

Family Supports

Consumers identified family as their parents, siblings, or if they had their own family, their spouse/partner and/or children. Consumers’ relationships with their families varied. A number of respondents had a good relationship with their family and there was frequent contact and support. Others had minimal contact and support. A third grouping of consumers described their relationship with their family as being strained and conflictual and the relationship was seen as a contributing factor to the consumers’ mental health problems.

Some consumers had positive relationships with their family and received support from them, emotionally, physically and financially. Consumers with these types of relationships had often been able to move back home when they had no place else to go and their family was there for them. As one consumer with a supportive family stated: “They helped out when I was stuck for a living situation.” Another noted that: “My parents helped out with my vehicle repairs.”

On the other hand, several consumers commented that they obtained little support from their families. In some instances this related to situations that occurred at home that caused tension in the relationships. Some consumers complained of unsupportive families

where the main issue centered on the controlling behaviour of a family member. Others identified experiencing verbal or sexual abuse from a parent or sibling that resulted in conflict and a negative relationship existing between them.

Parents or other family members often had limited information regarding the consumer's mental illness. This affected the relationship with their family member with the mental illness in a number of ways. Because of their lack of knowledge, they possessed little or no understanding of what the consumer was going through. Some held unrealistic expectations of their ill family member that caused conflict. One consumer put it this way: "They don't understand that I'm living within limitations. They think I should be able to just go out and take a course on anything that I want to or that I should be able to go out and make friends with just about anybody." When the consumer was ill, uninformed families had few coping strategies to contend with the consumer's behaviour, and this left them feeling vulnerable and uncertain as to how to help. As well they often knew little of the resources in the community that could assist them at these times.

It was not atypical for a consumer to have another family member with a mental illness also and this impacted their relationships in the family. One consumer had 3 family members with bi-polar disorder. This same consumer's stepdaughter had committed suicide. Another mentioned that: "I get along with my brother okay but he also has schizophrenia."

While uninformed family members were commonplace, consumers identified their relationships with their families improving when their families received information about their mental illness. One consumer who had a conflictual relationship with her

family said this: “They got some education on schizophrenia and now they are a bit more understanding and compassionate.”

Often consumers’ families lived far away in Alberta or in another province and this negatively impacted their relationships. In those situations, particularly when the consumer was on a fixed income, little contact occurred. Consumers usually could not afford to phone or visit their families, and over the years, the relationships waned.

No consumers interviewed were currently in a happy or satisfactory marital relationship. While a number were married in the past, all were now separated or divorced. One consumer was engaged to be married. Consumers interviewed were single, separated or divorced.

When consumers were separated from their spouses usually it was because they could not afford the legal costs associated with initiating a legal separation or divorce. This impacted consumers in terms of child custody status and financially. Any entitlement they might have for custody, alimony or child support was not realized, as the matter had not been pursued through the legal system. This resulted in them being in a state of limbo with these matters and their status neither clarified nor resolved.

Some participants had children but none had children who lived with them full time. Consumers with children typically spoke very positively about these relationships and emphasized how important they were to them. However, their experiences with having children were often fraught with problems such as access issues or financial problems.

Often consumers with children had legal problems related to these relationships. Usually they had no money to hire lawyers to deal with custody issues. They felt at the

mercy of the other parent in terms of times they were allowed to see their children. One woman left an abusive relationship and her children were with their father. She was very distraught about this but could not pay for legal services or have her children stay at her place as she could only afford to rent a room in a house. At the same time, her husband was living in her house that she owned after inheriting it from an uncle, but she could not afford to pursue a legal remedy to resolve the situation.

For another consumer with a teenage son, he had little contact with him. His son stayed with the consumer's mother in rural Alberta. Because there were no services there for this consumer, he was receiving services in Calgary. With being on a fixed income he could not afford phone calls to his son or the cost of bus fare to visit his son. Thus the relationship was seriously impacted and this was a source of great distress to the consumer.

Abuse by Family

While for many people one's family is a source of support and the relationships are important, a number of consumers had been abused by parents, spouses, siblings or adult children. Typically one parent had been the perpetrator of sexual abuse, usually on their female daughter, who was now a mental health consumer. These consumers believed their past history of abuse had significantly and negatively impacted them and some were receiving therapy to deal with this past abuse. The abuse seriously influenced their relationship with their parents, and in these instances, little to no contact with their parents was usual.

However, because of the shortage of decent, affordable housing in Calgary, some consumers were forced to move back to their parent's home, where the perpetrator still

resided. This was very distressing to those consumers. One consumer's experience illustrates this situation: "I was sexually abused by my father when I was a child and my mom did not protect me. I had to move back there as an adult when I was desperate for a living situation." Another consumer was abused by a number of different perpetrators while living at her parent's home. On one of these occasions, the perpetrator was an employee of her father's. This is how she described her parents: "(They were) not very supportive. Charges were not laid and I moved out on my own."

A few consumers had difficult relationships with their children, normally when their children were adults. Sometimes the consumer was estranged from their adult son or daughter. For others, they experienced conflict with their children and a few had been physically and/or verbally abused by their adult children. One was denied contact with her granddaughter, with whom she had developed a meaningful relationship, when her daughter had been abusive to her and the consumer had moved out of her daughter's home.

For example, one mother was abused by her adult daughter. The daughter had begged her mother to move in with her. This is what the mother said:

She'd (my daughter) shake me or you know, poke me real hard, or shove me back into a corner and grab me by my shirt and shake me...I was afraid that it would become really physical if I didn't get out soon and unfortunately what she did, she was doing in front of my granddaughter so she (my granddaughter) has a lower opinion of me now...and she hits me and calls me names if I don't do exactly what she wants and then she takes a screaming fit."

The consumer's psychiatrist told her she needed to move out of the home and referred her to a stress management group. Neither reported the abuse.

A few consumers were abused by a sibling, namely a brother. For one, her brother was her sexual abuser and this caused much strain in the family. In this instance, the consumer's parents did not believe their daughter. The parents still have a good relationship with the consumer's brother, and the consumer felt very unsupported.

Consumers who had been married also reported being abused by their spouses or ex-spouses, either financially or physically. For example, one male consumer's wife, when he was ill, had him sign over all his assets. Another was physically abused by her husband.

Support of Friends

Although a number of consumers did not find their families as supportive as they would like, they did have friends who were available to them and they very much wanted good friendships. However, of all the consumers interviewed, only a minority indicated that they had many friends. While some consumers had no friends, most had only one or two friends. In the majority of cases, these friends were other consumers with mental health problems. Loneliness was a very common and major problem for many consumers.

Consumers commented that they usually had lost their friends when they had become mentally ill or because of their mental illness, they had trouble getting along with people. One consumer stated: "I lost friends in the process of getting ill. I lost a lot of people who I thought were my friends...(Someone who I thought was my friend) behind

my back, called me a fucked up retard and I've known her for 4 years. She was my best friend."

The major place that consumers met people and developed friendships was at an agency where they were receiving services. It was commonplace for a consumer to be involved in a group or participate in social events offered at an agency, and this was a way that consumers got to know others. For a consumer who had many friends, she said this: "Yes, I have lots and lots of friends...from the 3 support groups here, from my writing club, from Life Skills now, from support groups out in the community and from my religious community."

Consumers usually liked having friends from the mental health community. One respondent's comments reflected those noted by many: "I have good friends and I have met most of them through groups...They know my story and they still accept me. They understand and are supportive. I can talk to them. They don't criticize but just accept me." Another indicated: "Those (friends) with mental health problems understand."

For others, while they had friends, they possessed limited finances to engage in activities with these friends. As one said: "Yes, I have friends but they have no money for leisure either." With the lack of money for transportation a problem for most consumers, just getting together with others also became difficult. One man commented that his friends live in the country where he used to live and: "They don't come to Calgary to visit."

A number of consumers had few or no friends. One's participant's remark mirrored those mentioned by others in the same situation: "I feel very lonely."

Summary

In this chapter, the findings and the analysis of the experiences of mental health consumers with supports raised identified an extensive list of themes and sub-themes. Supports were acknowledged to mean those services and assistance required for respondents to meet their needs, develop to their potential, and ultimately enjoy good mental health.

Formal supports included community programs, physician support and other supports such as financial, employment, leisure, transportation, legal and educational. Consumers identified components of programs and services that impacted them both positively or negatively and were related to their recovery. Program accessibility was primary concern and areas noted here included the need for flexible program hours, a good location, immediate access, program comprehensiveness and broadly mandated programs. Staff attitudes at the time of consumers contacting a service were factors as to whether consumers could or would access programs. Important factors that participants emphasized related to the programs' staff, were those of particular staff qualities, the staff's ability to deal with a range of clients and client behaviour, their knowledge and experience and the consistency of the staff involved in offering the services.

Respondents viewed their doctors as part of the formal support system. They identified issues related to physicians' relational skills, treatment expectations, physician's use of power, the area of medications, physician accessibility, and physician's knowledge-base.

Other areas of formal support were mentioned by the consumers and were revealing in terms of insights into their experiences with supports. The shortage of

adequate income was the paramount concern to nearly all the research respondents. In addition, the lack of flexibility in the current income support program to address special expenses and the disincentives in these programs to working, were noted. Accessing financial support when the need was urgent was a problem and assistance with developing budgeting skills was lacking.

Employment support was usually unavailable to mental health consumers except for those who received help with resume writing and job interviewing skills. Assistance to locate employment and hands-on help once they were on the job was rarely available. Identity and self-esteem issues were negatively impacted when consumers did not work and yet few had jobs or the hope of returning to the workforce.

Support in the transportation area was very limited or inconsistently administered. Most respondents believed they needed a bus pass but none had the money in their budget to be able to purchase one. This presented special hardships for them, whether it was trying to attend appointments, program or activities on foot, or when shopping for groceries and only being able to buy what they could carry home

Respondents believed it was important to be involved in leisure activities but their opportunities for leisure supports was limited. The cost of activities and transportation issues were two factors that impeded their involvement in leisure pursuits. Most engaged in some social activities offered by a mental health agency but at times they found this stigmatizing.

Participants who had attended post-secondary education usually had dropped out when they became ill. Most were unaware of services available at post-secondary

institutions to assist them or that accommodations could be made at the post-secondary facility.

Consumers identified legal supports as an area very relevant to them. Legal assistance when they were ill and in conflict with the law was important as was legal help with matters of family law. In both areas, respondents lacked knowledge about accessing legal services and the costs were also a major factor that prohibited consumers retaining the services of a lawyer.

Finally, participants clarified the importance of having informal supports in their lives such as family and friends. Loneliness was a big problem for many consumers, some family relationships were abusive, and consumers liked having friends who were also consumers as they felt they were able to be understanding as to what the consumer had been through.

CHAPTER SIX

CONSUMERS' PREFERENCES FOR HOUSING AND SUPPORTS

In this chapter, the findings regarding consumer preferences related to housing and support services are presented. Gaining an understanding of consumers' experiences with housing and support services was important as this information had not been previously solicited and was not available to inform policy and programs. Most of this data identified the negativity of consumers' experiences. While these findings were not known ahead of time, this researcher believed consumers could also inform decision makers and the mental health service system as to what they would prefer in the areas of housing and supports. Consequently, an additional part of this research was to hear what consumers had to say regarding their preferences in these two areas. These preferences are outlined next.

The data obtained from consumers regarding their preferences for housing and support services were less extensive than that related to their experiences. This reduction in data seemed to be for two primary reasons. First, when discussing their experiences with housing and support services, for many consumers, this had been their only opportunity to speak and tell their stories, so the majority of the interviews were taken up with this discussion. Second, consumers seemed to be so caught up in their mental health problems, their state of poverty, and trying to manage their daily lives that few had the opportunity to have hope and to consider what housing and support services should look like. One respondent, when asked about her preferences had this to say: "Why dream? Why hallucinate, you know? Why put myself through that when I know I have food in my fridge, I've got a roof over my head and I've got a key to my door where I can walk

in anytime I want.” However, that being said, consumers did provide salient information as to their preferences related to housing and support services.

Preferences Regarding Housing

Consumers indicated various themes regarding their preferences in the area of housing. Major preferences identified related to a need for a housing referral service, preference for supported housing and a need for affordable housing. Respondents discussed the preferred location of housing, the preferred size of housing, and the preferred condition of the housing they would like to live in. As well, participants commented on the preferred ways that the mental health system and housing agencies could interact with one another and preferred services they would like to see to address concerns when moving from one type of housing to another. These data are summarized in Table 6.1.

Table 6.1
<u>Consumer Preferences Regarding Housing</u>
The Preferences
A housing referral service
Independent living
Normalized housing
Affordable housing
Larger housing
Well maintained housing
Moving assistance
Strong linkages between the housing and mental health systems

One preference identified by some consumers related to having a centralized housing referral service. Consumers found it difficult to locate housing and noted that depending on the type of housing that one was looking for, one had to go to many different places in the city. A centralized registry did not exist, nor did one organization or agency manage housing exclusively. Thus, locating housing was a complicated, time-consuming, costly and frustrating process and it was felt that one agency, at a centralized location, with a centralized housing registry would be beneficial.

In every instance, all of the consumers preferred to live in an independent apartment or house. Consumers overwhelmingly indicated that they wanted to have their own place and not have to share it with someone else. Many consumers indicated that while they wanted their own place, they also wanted services they required to be available in their own homes. Thus, the concept of supported housing was central to them having their own home.

Consumers also preferred their own place so they would not have to contend with rules or various policies associated with living in units managed by housing agencies or mental health agencies. Consumers expressed frustration with having to move when they no longer met the requirements of some housing for reasons such as a change in income, a change in their mental health (either an improvement or getting ill again) or because their children were no longer living with them. As one consumer put it:

I do not want to move based on the number of kids. It's very destabilizing for my mental health...There is no flexibility in the system. I need a permanent home and I've been here 6 years but I will have to move when my son turns 18 in 2 years.

Don't make these places temporary. This is my home as opposed to its temporary based on how many children I have with me.

Related to these concerns was a preference for housing where one could have pets. Numerous consumers had a pet and wanted to keep it but found it nearly impossible to find housing either at market value or subsidized, where pets were allowed. One consumer said this about pets: "As for having pets, it's important to the mental health of some people. It's not just a luxury."

Consumers recognized the difficulties associated with obtaining safe, affordable housing in Calgary, that was in good condition and well-maintained. These issues were compounded by the fact that the majority of mental health consumers interviewed received a fixed income and had little money to live on. Thus, consumers, without fail, preferred to have housing available to them that was subsidized so as to be affordable.

Research respondents wanted housing that was dispersed throughout the city. This was in contrast to housing available in Calgary for people with a low income or mental health problems that was segregated, that is, all located in one apartment building or located in one area of the city (e.g., the downtown core). Consumers perceived a stigma associated with apartment buildings that housed only one type of clientele or groups marginalized in our society.

Consumers preferred housing that was located in decent areas of the city, areas where they could feel safe. As one consumer put it: "I find it very offensive and very stressful that a lot of these low income housing units and places are in areas that are unsafe and that you really wouldn't want to live in...Low income housing needs to be in better areas of the city."

One respondent, from a rural area in Alberta, desperately wanted housing made available for people with mental health problems in rural areas. For this individual, no such accommodation existed, and he had had to leave his son, a rural way of life, and his home community to access supported housing, only available in the city.

Most consumers preferred housing where the size of the unit or house was larger. Many consumers had or were living in subsidized units that were very small in size and they wanted a place to live that was roomier and which would accommodate full-size appliances and furniture. As one consumer said: "I need more space." Another echoed this in her remarks that: "I need a larger place where you can have your own stuff."

Research respondents wanted to live in housing that was in good condition and well maintained. Because of their limited financial situations, many consumers lived in places that were not looked after and were in poor condition. One consumer remarked that housing for consumers: "Needs to be nicer."

Consumers preferred that the housing systems and mental health systems work together instead of operating unilaterally with no coordination. Consumers spoke of each of these systems not communicating with one another and that this was problematic for consumers. One respondent said this: "The housing and mental health systems need to work together."

A secondary concern about these two systems was a perceived lack of flexibility in working with people with mental health problems. Policies and rules were viewed as restrictive and these two systems could not respond to consumers whose circumstances were somewhat unique. Consumers wanted these systems to be more accommodating and consider the individual needs of applicants. As one participant noted: "There is no

flexibility in the systems.” Another illustrated her experience in trying to obtain subsidized housing after leaving her home which she owned while fleeing an abusive husband: “I have to have my own place but I don’t qualify for subsidized housing because I own a home which my husband occupies. And yet I have no money, and no money for lawyers to get myself back into my house and my husband out.” Essentially she found herself ineligible to qualify for subsidized housing and yet her only source of income was A.I.S.H..

Respondents indicated they would prefer that an organization or program existed to assist them when they were moving from one house or apartment to another. The majority of consumers moved frequently, for a variety of reasons, and they found this experience particularly stressful and negatively impacting their mental health. The type of support they desired when moving fell into the areas of physical assistance such as help with locating a mover, packing, and cleaning their place after they had moved out to financial assistance and support to pay for the cost of the move.

Preferences Regarding Formal Supports

Mental health consumers identified a number of preferences regarding formal supports. Themes discussed were preferences related to accessing services, the availability of services, the amount of services one could obtain and the gaps in services in the city of Calgary. Consumers strongly endorsed a preference for community-based services. Consumers also expressed preferences about certain aspects of services. This information is presented in Table 6.2.

Consumers also wanted services to assist them with the areas of employment, legal matters, leisure, and transportation. Considerable important themes emerged

regarding respondents' preferences related to their finances. Finally consumers indicated a preference for more extensive research to be undertaken in the area of mental illness.

Table 6.2

Consumers' Preferences Regarding Formal Supports

The Preferences

Accessible services
 Staff assistance when entering program
 Supportive/empathic staff
 Flexible, non time-limited supports
 Home-based supports
 Community-based supports

Consumers preferred services that were easily accessible. The concept of access included the location of the service, the hours of the service, the time required to obtain the service, the amount of service, the mandate of the service, the cost of the service, and accessing services where stigma was not an issue. Consumers preferred services that were in a location that they could avail themselves of them easily, namely in their home communities. Consumers wanted services that offered flexible hours, evening programs, and weekend services. Respondents expressed the desire for services that they could obtain when they needed them, with little or no waiting time required. As one consumer remarked after suffering with no means of financial support: "The system overall takes too long to make decisions. I had to wait 3 months before I was considered for A.I.S.H." Another said this: "Nothing happens until you crash...When you crash then things start happening...Before I was trying to go to agencies (to get help)...I needed help but well

I'm sorry you don't have a major mental illness, we can't help you." Another, who waited a long time to access psychological services because the agency paying for the service would not approve it until she had been thoroughly assessed again said this: "(They) need to accept diagnoses from other provinces instead of having to be re-assessed." Respondents particularly indicated a preference for being seen immediately during times when they were experiencing a crisis.

Consumers wanted services that possessed a broad mandate so that they could receive a variety of services from one agency. Research participants desired services that were free, as the limited financial means of most consumers meant they could only participate in receiving services when there was no cost attached. Along with their preference for free services was also the preference for accessing any service without cost being a determining factor. In other words, consumers perceived that some services they required were unavailable to them because they could not afford them (e.g. private practitioners), and they wanted to have the full range of services available. One respondent who was denied services from an agency as she was not deemed to be "sick enough" said this: "I was told to go to these counselling things. Well these counselling groups take money and that's one of my problems. I don't have any money."

Still others noted a need for a central place that one could go to receive information about services in the city. Consumers preferred that this type of agency also provide assistance in referring them to the appropriate place for receipt of services.

Consumers preferred that certain dimensions of some programs and services were altered. A number of respondents noted the difficulty for them of entering a program on their own. They indicated they preferred some assistance with this. One consumer's

comments echoed those mentioned by others: “There should be a welcoming group as it’s hard to break into an agency. When someone new comes in, to make friends with them, and introduce them to other people, you know, and generally inaugurate them into the group. I felt lonely and isolated.”

Participants wanted the staff providing programs and services to be more empathic and provide more support. One individual commented about the staff in this way: “(We) need more emotional support, continuity of workers and more psychiatry time...More compassionate psychiatric emergency staff.”

Consumers preferred that there were more services available as they viewed Calgary as having a shortage of services in a number of areas, as evidenced by the lengthy waiting lists of some services, programs and agencies. They did not view similar services as redundant as they believed that the long wait lists were proof that not enough services existed or that services were under resourced and thus could not deal with the demand. For example, one consumer’s comments were reflective of those noted by many: “I couldn’t access (the agency program) for 1 1/2 years.”

Consumers particularly identified a need for more support services in their home and this was their preference. One consumer put it like this:

I don’t think you can just build a building and house...people with mental health issues and just leave them alone. There needs to be a system that they’re not just housed and forgotten and that’s what’s happened...At one place, they just put them in there and they are forgotten about.”

Consumers preferred services that were not time-limited and were flexible. Often they felt their needs were such that the specified time allowed for the service was not

adequate. For example, some consumers receiving therapeutic services felt their issues were not necessarily conducive to being appropriately addressed in a 6 or 8 week group, or 3 months of individual sessions. As one consumer noted, after only being able to access a service for a specific time period, for her abuse: “I needed more time but the sessions were only short-term.”

Others found that with the cyclical nature of their mental health problems they require required services for various lengths of time yet services were typically time-limited and of a one-shot nature. The intensity of the services was frequently also an issue for consumers. Respondents preferred services that were as in-depth as they required and they often felt the services they were receiving did not meet their level of need. One consumer stated it like this: “I feel that the programs should be more in depth.”

Consumers interviewed identified a number of gaps in service and articulated what they would prefer in these areas. These findings are presented in Table 6.3.

Table 6.3
<u>Ways to Address Gaps in Service</u>
The Ways
Community-based crisis stabilization unit
Moving assistance
Services for higher functioning individuals
Assistance with daily living tasks when ill

A crucial service that was lacking was a crisis service available that addressed the gap between contending with a crisis in ones own home and having a hospital admission. Consumers preferred that there was a place they could go to in the community where they could stay overnight if necessary, and have their situation or condition stabilized before returning home as indicated in the quote below:

Some place between hospital and community, a safe house. You're out there having to deal with the community whether you can handle it or not. Or there's the institution. There's nothing in between. And that's where we have failed us, the people who have psychiatric disabilities. There should be a safe house...and you can go and say I am not coping and until I get stabilized on my medication or until these voices stop or these delusions stop or I'm emotionally at a point where I don't feel like I'm going to harm myself, I need a safe place to stay...A temporary accommodation.

A gap in service noted was a need for an agency that could provide assistance with moving, an aspect that was viewed as important. One respondent stressed: "We need a service to help with the practical aspects of moving." Others preferred a grocery delivery service, mainly because they could not afford to use public transportation or had difficulty getting out for shopping in the winter months. One woman said this: "I need a service to help me get groceries in the winter. Homemakers at one time did this but this is not now covered under homemaker services."

Another gap in service related to a preference by some for services to be available for higher functioning people. Some people had been receiving services at various times for a number of years but were functioning at a level that they required more than what

was available. A number of consumers' comments in this regard were captured by these remarks: "I feel that there should be groups here aimed at the more higher functioning people with mental problems...What we're doing right now is anger management...It needs to be a little bit more confrontational with more constructive feedback."

A further gap in services that consumers mentioned, related to a program becoming available that could assist people, when they were decompensating, to help them with day-to day tasks. One woman explained it this way: "It's a hit or miss situation. When an adult gets sick, they need a service to provide for the kids in their own home, look after the home and pay the bills."

Consumers preferred services that were located in the community and had a community-based orientation. They also stated a preference for using services in their home community, similar to any community citizen. This approach was stressed by the comments of many consumers but this is what one remarked about having access to a community health clinic close to where she lived downtown: "There should be more community services like 8th and 8th. I don't have to go through the hospital. It's better that way. They also have a mental health worker there so if I need to talk to her I can do that without having to go through the hospital system."

Consumers indicated three preferences that related to the area of employment support. These are presented in Table 6.4.

The first preference was in regard to job placement for mental health consumers that typically was provided by a community agency. Consumers wanted job placements that were based on their individual needs. For example, consumers able to work wanted the hours of work more individualized. Some consumers were able to work longer hours

than they had been provided with while others actually needed a shorter workday because of their mental health problems. Yet consumers found they had little control over this. One individual said this: “I would have liked longer hours.”

Table 6.4

Preferred Employment Supports

The Employment Supports

Individualized job placement assistance

Appropriate job placements

Assistance with obtaining job site accommodations

For others the type of work they had was the issue and again consumers indicated they wanted their individual knowledge and skills to be taken into consideration. Agencies assisting them in job location had a tendency to locate work where consumers felt underemployed. One respondent's comments illustrated this concern: “I needed a better job placement, more intellectually stimulating. I mean factory work is not my kind of work. I'm an artist and factory work does nothing for me...I cannot spend all day wiping headphones. I can't do it.” Another reiterated these comments when she discussed her job placement experience: “The jobs themselves were all mindless.”

A third preference related to employment for consumers was for there to be some assistance available for them related to ensuring job site accommodations. Because of the nature of their mental illness, many consumers who wanted to work felt they needed someone to work with their prospective employer to pave the way for the consumer at the

work place. One respondent's remarks reflected those made by others: "So I think what's lacking is an employment liaison (person) between people with mental health issues and the employer. Because I'd like to explore having a job again, but I also know that there are times where I'm not going to be coping and I'd like to be able to make the employer aware without scaring them to death."

Three themes emerged regarding consumers' preferences in the area of income. These are summarized in Table 6.5.

Table 6.5
<u>Preferred Financial Supports</u>
The Financial Supports
Increase in financial assistance rates
Flexible financial assistance programs
Quicker screening when applying for financial assistance

The most frequent preference expressed related to the need for a significant increase in both A.I S.H. and Social Assistance rates to more adequately address the financial needs of consumers and for consumers to be treated with some dignity. One consumer who had serious concerns about the low A.I.S.H. rate and who thought it should be increased made this observation: "I think it's a shame to expect people who are human and have a body and soul to live on \$800.00 a month. I think that's very unfair. Those people don't deserve to have to live in squalor...They should be able to live with dignity. But they can't. They have to go bum clothes." Another, who felt the same way, and who was receiving social assistance remarked in this manner: "As far as social

services is concerned, they've done their thing. They've given me my \$229.00 for the month and it's not their fault that I can't stretch it far enough." Other respondents preferred that there were subsidized bus passes and recreation passes for mental health consumers to augment their financial needs.

A number of participants expressed a preference for there to be more flexibility with both the A.I.S.H. and Social Assistance Programs, where individual needs and circumstances were taken into consideration. Consumers cited numerous examples where the income rates were fixed and did not take into account their special state of affairs. One consumer had his young daughter living with him on weekends, yet no extra monies were available to him on A.I.S.H., even though he incurred extra costs at these times. He found his income close to impossible to manage on because of this. Another said this: "There needs to be more flexibility with A.I.S.H. to pay for moving or storage costs."

Consumers accessing these programs preferred a much quicker screening of applicants as many endured long waiting periods during which they had no source of income whatsoever. Respondents' felt that the agencies that administered these programs were under resourced, required more staff, and that this was necessary to address the problem of long waiting periods associated with determining eligibility. As well consumers wanted it recognized that, in their opinion, the charge related to obtaining prescriptions was unnecessary, a financial hardship for consumers on fixed incomes and needed to be scrapped. One consumer remarks were these: "They have this new thing...The first three prescriptions you have to pay \$2.00 for and then they give you five bucks for that (if you are receiving social assistance)...I'd either abolish that or make the

dollar advantage to the welfare client.” For those receiving A.I.S.H., they had to find the money in their budget to absorb the prescription costs.

Many consumers felt bored and lonely and they wanted to engage in leisure and recreation activities. However they were frequently prohibited from doing so because of their difficulties in accessing activities. Their preferences to address this concern fell into two areas. The first related to recreation and leisure programs offered by agencies to be more flexible in terms of times when the activity was offered. For example, an exciting leisure program might be available but it would only be offered on one day of the week. If the consumer already had a prior commitment at that time, then they missed out, and there was no other option available to them. One individual desperately wanted to attend a Friday leisure program offered at an agency but had another commitment on that day. He felt frustrated and had this to say: “The activity day there (at the agency) needs to be varied as I cannot attend Friday activities.”

Secondly, consumers wanted subsidized bus passes to aid in one having the ability to get to the activity and subsidized recreation passes so they could participate in an activity without cost preventing them from attending. One consumer commented like this: “I need a discount card for leisure activities like for the city pools at Lindsay Park.”

Most consumers interviewed were dependent on the public transportation system in Calgary in order to get around the city. However the prevalent theme regarding transportation was the prohibitive cost of a bus pass to use the public transit system and a preference for a subsidized bus pass for people with mental health problems. With few exceptions, consumers could not afford to purchase a monthly bus pass because of its cost and their limited financial means. Thus they endured hardship in accessing services

within the city. One consumer's plight was illustrative of the problem: "I had no money for the bus and I had to walk to the...clinic for my first appointment. I was in really bad shape and suicidal." A subsidized bus pass was something that consumers felt was very important and something they felt would be of great assistance to them.

Like any community citizen, consumers experienced their share of legal problems. The difference for them was their inability to access legal services, when required, to resolve these legal problems. Because of their limited financial means, contacting a lawyer to handle their legal concerns was not a realistic consideration. Some of their legal problems resided in the area of civil law so applying for Legal Aid, which only deals with offering financial support for people involved in criminal matters, was not an option. Consequently, their preference was for free legal services to be made available to them to assist them with their legal issues.

In addition, consumers also found themselves in situations where they had little knowledge that their legal rights were being abused or what legal remedies might be available to them to deal with situations they found themselves in. This was compounded by the fragile state of their mental health, at a time when they felt vulnerable and least able to handle situations. Thus, in combination with their preference for free legal services, also was a need to have access to good legal information. Their preference was for these types of legal services to be located at one place or attached to one agency to facilitate easy access.

A final preference identified by some consumers related to the area of research. Consumers wanted researchers to be able to find a cure for their particular mental illness and for there to be more of an emphasis on funding research in the mental health area.

Summary

When consumers were asked to indicate their preferences with respect to housing and supports, they articulated what they wanted in a number of areas. In addition, they indicated that they hoped their wishes and desires would be heard and seriously considered by those individuals in positions of policy and program development.

Housing was an urgent area of need for consumers, due to the shortages of suitable, affordable housing in Calgary. Respondents wanted a housing referral service and preferred to live independently, they wanted normalized housing that was larger than current subsidized housing units and housing that was well-maintained. They also wanted supported housing. They also preferred that there be strong linkages between the housing and mental health systems. Finally consumers indicated a need for assistance across a number of dimensions when they had to move houses.

Respondents preferred supports that were more accessible across a variety of dimensions. They wanted program staff to assist them when they were new to a program in terms of facilitating their entry into the program and they also wanted staff to be empathic and supportive. Consumers preferred supports that were flexible and not time-limited and that were both community-based and home-based.

Respondents also identified a number of service gaps. They preferred a community-based crisis stabilization unit, assistance when they had to move residences, more individualized services that also addressed the needs of higher functioning consumers and assistance with daily living tasks when they were ill.

Participants indicated needs in the employment support area. They preferred assistance with job placement that was individualized, they wanted appropriate job

placements that coincided with their knowledge, skills and credentials, and they needed help once they were on the job, that is with working with their employer and colleagues regarding job site accommodations.

The financial area was another area of paramount concern and consumers articulated three major areas of need. They wanted increased financial assistance rates, flexible financial assistance programs and quicker screening when they were applying for financial assistance. In addition they wanted financial assistance for the costs associated with obtaining prescriptions, bus passes and recreation passes and suggested that these be funded by either the provincial or municipal governments.

Respondents indicated a preference for more flexible and varied times for the offering of leisure supports and a bus pass that was paid for so that they could not only access leisure services but more importantly travel around the city to obtain the services they required. As well, consumers indicated a desire for assistance in the legal area including free legal services and they wanted the ability to obtain good legal information at one centralized location.

CHAPTER SEVEN

DISCUSSION AND CONCLUSION

This research focused on adult mental health consumers who had experience with housing and the mental health system. The purpose of this research study was twofold: 1) to gain an understanding of the experiences of mental health consumers in Calgary regarding housing and supports and 2) to learn about their preferences with respect to housing and supports. With this knowledge, it was hoped that mental health policy, practice and programs could be impacted to more effectively serve the needs of mental health consumers.

Although research data exists regarding consumers' preferences associated with housing and supports, it is limited, primarily American, quantitative in nature and often reflective of the opinions of professionals working in the mental health system. Little research was found where the data were directly solicited from consumers and which addressed, specifically, consumers' experiences with housing and support services,. What this study did then, was bring forward the consumers' voices with respect to what had happened to them in the areas of housing and support services and what they would prefer in these two areas.

Based on the information provided by the research respondents in this study, a number of important findings emerged. Consumers wanted normal housing that was stable and permanent. Consumers did not want to be moving from one residence to another because they no longer met the eligibility criteria of a certain housing provider. Consumers also wanted housing which was affordable, which for most, meant subsidized

housing. Respondents indicated that housing for them must be dispersed throughout the city, located in decent areas, and safe.

No one wanted housing where everyone living in a building had mental health problems. They preferred housing where there was more space in the unit than the current subsidized units, which were perceived as too small. Participants also wanted housing that was well maintained.

In addition, they indicated a need for an agency to exist which provided a central registry of housing available in the city. This was seen as important in assisting them in locating suitable housing. They desired immediate access to appropriate housing and they wanted choices regarding their housing.

Respondents preferred a place of their own, with no roommates. Living alone but receiving support services that they required was their wish. Services that were offered in their home or home community were most desirable.

Regarding support, consumers wanted services to be much more accessible, community-based and offered consistently by the same staff. They desired programs that met the diverse needs of consumers. Consumers wanted staff to be well trained, knowledgeable, experienced and skilled as well as very professional in their behaviour. However, staff who were strong on being caring and compassionate, who were supportive and were good listeners and who displayed hope for the consumer were also what consumers were looking for.

Poverty was a tremendous problem for nearly all consumers and severely impacted their lives in a negative way. Consumers indicated that they required increased rates from organizations that provided income to them and subsidies related to public

transportation and leisure services. Employment services needed to be much broader in what they could offer and on the job support and assistance was viewed as essential. If pursuing educational opportunities, consumers required post-secondary institutions to provide accommodations for them based on their individual needs.

More accessibility to doctors, in the consumer's home community, and consistently having access to the same doctor were important to consumers. Respondents strongly desired emergency, short-term crisis care in the community so that they did not have to utilize institutions. In addition, they desired that the medical community provide more information to consumers regarding diagnosis and treatment including medication. Consumers wanted doctors to be more knowledgeable about non-medical treatments (e.g., psychotherapy), services and issues impacting consumers. Again caring, supportive attitudes on the part of physicians were seen as imperative to effective treatment.

Consumers identified the need for support from family and friends, which they viewed as essential in their recovery. However, they also needed acknowledgement from professionals that at times, some family relationships were damaging, and promoting family contact in these situations was problematic. Additionally, while friends were important, consumers did not want to live with their friends or other people.

Consumers required access to legal services to deal with matters of civil law. Services needed to be free, centrally located and staffed by lawyers willing and able to provide legal education, assistance and advice.

Finally, consumers wished for there to be more public education to reduce stigma. Further funding for research to address the causes and treatment of mental illness and which addressed other mental health issues was perceived as required.

A Reconceptualization of Housing and Supports

Little data have existed that was generated from mental health consumers regarding their experiences and preferences in the areas of housing and supports. This research definitely indicates that mental health consumers can provide valuable insight into their needs. The results of this exploratory study, where consumers were the research respondents, raise serious concerns about our current systems of housing and supports.

While the findings' chapters on the areas of housing and supports were presented separately, these two areas are connected to one another. Clearly, both mental health consumers' housing and the supports they require to enjoy good mental health and to function in society, are related to one another.

From the analysis of the data, the results strongly suggest more could be done for mental health consumers. Many factors surfaced which help in reconsidering conceptions of housing and supports. These, in turn, have implications for planning and providing housing and support systems.

In 1993, Trainor, Pomeroy and Pape offered a framework for support, which located the consumer in the centre of a community resource base. They went further than traditional models by suggesting that formal mental health services, families and friends, generic services and supports and consumer groups all need to be included when considering how to assist consumers with improving their mental health. At the same time they indicated that consumers should have access to the same elements as any citizen in order to live fully within the community: income, work, housing and education.

Their model is mentioned here as the results of this research support their conclusions. However, the data obtained expand the above researchers' model in two ways. First, an addition to the elements they indicate in their model is the area of leisure. When enjoying full citizenship in the community, leisure is a necessary component. Secondly, this research begins to delineate consumers' ideas about specific components of both the areas of housing and support that Pomeroy, Trainor and Pape (1993) articulated.

In an earlier chapter, various theories were discussed that were associated with both explaining the etiology of mental health problems and how to intervene. The findings of this research seem to be most closely aligned with the theoretical perspective of intervention called psychiatric rehabilitation. The concepts of this perspective that focus on mental health consumers integration into the community, their functioning at their fullest potential, while emphasizing addressing the many dimensions of human need all relate to what mental health consumers in this study told us they wanted and needed to participate with fully in society.

Social-stress theory also ties in with the findings of this study in that it focuses on stressors in an individual's external environment that can contribute to developing mental health problems or having a recurrence of symptoms. A number of consumers mentioned that without adequate housing or with having to live in a stressful living environment, that they often had experienced a deteriorating state of their mental health.

It must be recognized that mental health consumers are individuals. The nature of their mental health problems, how they respond to their problems and the interventions that are effective all vary from one consumer to another. However, that being said, the

research data clearly indicated directions to move towards in the areas of housing and supports.

Like other disability groups, mental health consumers want to live independently, in permanent, normalized housing and in a living environment that they can call home. They require flexible supports that are provided in either their home community or their actual home.

These consumers' responses emphasized that there are many dimensions to their rehabilitation, adaptation and recovery from a mental health problem, and that the cyclical nature of some mental disorders has implications for the supports that they require. The medical model is only one component in all of this. A recognition of the role of appropriate housing in coping with mental health problems and the use of much broader-based social interventions to aid in rehabilitation and recovery is vital.

Both formal supports (i.e., the mental health service system) and informal supports are factors in how consumers cope with their problems and succeed in the community. Consumers indicated that the availability of formal supports is, in and of itself, not nearly enough to ensure success. Consumers suggested that there are various factors within programs that are critical in assisting them: (1) factors related to accessing the programs, (2) factors related to the staff involved in program delivery, (3) the actual focus and content of the program, and (4) the effectiveness of the program.

Consumers were informative when indicating that the concept of supports is multi-dimensional. To date, service providers have taken a somewhat narrow and limited view of what constitutes support for consumers. Consumers identified marked gaps in

service and emphasized needs in such areas as assistance when they were moving residences, in the transportation area, legal area, employment area and educational area.

Consumers strongly suggested the need for better financial assistance programs including an increase in rates and flexibility in the programs. They believed there was a relationship between living in poverty, having mental health problems and coping effectively with mental health problems.

While this exploratory study has generated a number of important results, it also is only a beginning and points the way for future research directions. Research participants responded in their interviews by using language such as feeling satisfied with a program, that a certain model of housing was effective or that this type of support aided them in their recovery. Further research that seeks to clarify what consumers mean by these terms and the relationship to rehabilitation and recovery is required.

As well, a beginning was made with this research in identifying those dimensions of supports that made a difference to consumers in their rehabilitation and recovery. These need to be explored in more depth to ascertain which dimensions are indeed related to improvements in a consumer's mental health, rehabilitation, recovery and community integration.

Finally, respondents suggested components of programs that made them effective. This area as well should be examined more thoroughly. We are just beginning to evaluate programs as to their effectiveness. Research that focuses on the areas that this research identified as variables to use in program evaluation (e.g. accessibility, factors related to the staff) should be pursued.

Strengths and Limitations of the Study

There were a number of strengths of this particular research that can be noted. Most important was that mental health consumers in Calgary, Alberta, demonstrated quite capably that they can indicate their experiences and needs in the areas of housing and supports. Little Canadian research exists on consumers' experiences and preferences with housing and supports, and most of the research available is taken from the perspective of professionals/service providers or family members (Hammaker, 1996). While these perspectives are important, so are the voices of the consumers, the individuals on the receiving end of housing and support services. This research helps tremendously in understanding housing and supports from a consumer's perspective.

Secondly, mental health consumers had the opportunity to tell of their experiences with housing and supports and discuss their preferences in these two arenas. Their voice was heard and listened to and this has seldom happened in the past. Using a qualitative methodology provided a definite richness to the data and an extensive descriptiveness, which would not have been evident to the same extent, had the study been quantitative.

Some limitations were evident. Respondents were asked to discuss their experiences and preferences freely, and questions were open-ended. The researcher was consciously aware that by virtue of asking questions, she might be framing the responses that were forthcoming. Every effort was made to be careful in this regard and to have an unstructured interview with each respondent but possibly other themes would have emerged had different questions been raised or answers/discussions explored in another way.

The same holds true in the area of data analysis. Although transcripts were typed verbatim from the actual interview that was audiotaped, data analysis is an interpretative

process. Scrutinizing the data and selecting out themes is an act of interpretation. While the researcher had other individuals examine some of the transcripts and identify themes to assist in addressing any possible bias, important areas could have been overlooked.

The sampling procedures including sample size could have produced a very selective group of respondents, unique in a variety of ways. All respondents were receiving services at the same agency, although this agency is one of the largest in Calgary that serves individuals with mental health problems. What was evident was the majority of respondents were in the 25-45 year age range and Caucasian. Thus older consumers, those just entering the adult mental health system and possibly moving out onto their own, or individuals of colour, were not represented in this study. Their experiences and preferences may differ from the group sampled but their data were not available.

None of the research participants were employed, all were on fixed incomes and only one owned her own home. It is recognized that other individuals with mental illness do work and are self-supporting, but this group did not appear in this sample.

All respondents participating in this research project self-selected or volunteered. As well, some agreed to participate in the study after being identified by a staff member or consumer as someone who the researcher should talk to. It is likely that those that chose to be involved with the study were different than those that chose not to be a part of this research. What was noticed was that many interviewed were quite passionate in their remarks and genuinely wanted the opportunity to tell their stories and what they had experienced.

The issue of respondents feeling free to be open and honest with the interviewer was a small concern. The interviewer attempted to build rapport with the respondents right from the beginning when she met with the various groups to solicit respondents. This continued with time being taken at the beginning of the interview and throughout the interview. Participants were also reassured that what they said would be kept confidential. An asset was that the interviewer was experienced and very comfortable in interacting with individuals with mental illness and this facilitated the process. However, rapport-building and developing trust had to occur in a condensed time frame, possibly impacting how free some respondents felt in discussing their situations.

Interviews were also held at the agency where the participants were receiving services. Some were concerned about the agency staff finding out what they were talking to the interviewer about. Interestingly, all the consumers were extremely favourable in their remarks about this particular agency and the services they received, notably more than for any other service that they mentioned. However, from actually undertaking the interviews herself and thus being present during the interviews, the interviewer, when analyzing the data, felt these positive experiences sincerely reflected what the consumers thought about the services and supports they had received at this agency.

Links to the Existing Literature

One component of this research study was to compare the research findings to existing research discussed in the literature review. A number of related studies exist. However, it must be recognized that while focusing on a similar subject, they deployed different sampling techniques, different research methodologies and examined somewhat

different variables. Thus, while these findings have been compared to the literature, consideration must be given to these differences.

The conceptualizations' of various authors regarding the philosophy, elements and components of a comprehensive community support system (Carling, 1995; Nelson, Walsh-Bowers Hall, 1998b; Trainor, Pomeroy & Pape, 1993; Wilson, 1989), and consumers' needs and preferences in the area of supports (Hammaker, 1996; Marsh, Koeske, Schmidt, Martz & Redpath, 1997) are upheld by the testimony of the research participants from this research study. Services that are community-based, consumer-focused, and multi-dimensional and those that move beyond a strictly medical model were all indicated as important in addressing consumers' mental health.

Housing Literature

Consumers, in all instances, preferred community living over living in an institution, consistent with Davidson, Hoge, Godleski, Rakfeldt and Griffith's (1996) findings. The quality and appropriateness of housing was seen as imperative for consumers, in this study, in their recovery process. These data are consistent with the studies undertaken to date (Baker & Douglas, 1990; George, 1995; Srebnik, Livingston, Gordon & King, 1995). Respondents also wished for safe, well located housing, similar to what Massey and Wu (1993) discovered in their research.

One unique finding from this research related to consumers' desiring stable housing, meaning long-term housing that they viewed as their home. Consumers frequently had to move for numerous reasons, and they found this distressing and negatively impacting their mental health. Respondents wanted their homes to be there

even if they had a hospital admission. They also did not want to move because their financial or personal circumstances changed.

Respondents also desired housing that was located in decent areas of the city and yet often this was not the case. Respondents also indicated a need for housing that was more spacious. Most subsidized housing was very small and this impacted consumers in terms of their mental health and how they lived. The small size often precluded the consumer having much furniture, or his/her own furniture. Often there was no oven and only a small fridge with no freezer, and this influenced consumers' ability to cook nutritious and inexpensive meals.

In terms of the type of housing consumers preferred to live in, residing in their own home by themselves, was explicitly their desire. This major finding is supported by the quantitative research undertaken in this area (Keck, 1990; Livingston, Srebnik, King & Gordon, 1992; Massey & Wu, 1993; Tanzman, Wilson, & Yoe, 1992; Yeich, Mowbray, Bybee & Cohen, 1994). These respondents also wanted housing that was normal. Living in apartment buildings where everyone else was also a mental health consumer was definitely not their preference.

For those respondents needing a roommate for both company and to share housing costs and in those instances where their roommate was another consumer, participants in this study suggested that there needed to be services available to assist them when their roommate experienced a recurrence of symptoms. Respondents spoke of living with another consumer as a relationship that could work well, except when one or both of them got ill. Consumers stated some assistance was available for the consumer experiencing an episode but not for them. In-home support was required but none

indicated that the mental health system recognized this problem nor were services available to them for dealing with this type of crisis.

Consumers who experienced living in rooming houses commented that this was the worst type of housing. The poor of condition of the housing and the fact that other tenants were involved in drug and alcohol abuse and/or criminal activity were undesirable facets of rooming houses. Consumers noted that they lived in this type of housing only because it was inexpensive. This finding is consistent with those of Tanzman, Wilson and Yoe (1992) who found single-room occupancy held the least appeal for mental health consumers. These results are contrary to the research of Linhorst (1991), though, who found that single room housing was a desirable alternative for consumers in that it offered independence and the opportunity to socialize.

In this study, many consumers, at one time, lived in group homes. While some commented that the structure in the group home setting was helpful to them in terms of improvements in their mental health, all preferred the concept and experience of supported housing. One finding in this study was that sometimes an issue in group home living related to appropriateness of the placement. Some consumers felt they were functioning at a higher level than others in the home, yet staff were not able to acknowledge this and be flexible. Thus some consumers felt that while they were more independent, skill-wise, than others living in the home, that they started to lose these skills and become more dependent. This is consistent with the findings in Segal and Moyle's (1979) study.

Only one respondent lived in a room and board setting and he disliked his living arrangement. Other researchers (Nelson, Hall & Walsh-Bowers, 1999; Nelson, Hall &

Walsh-Bowers, 1998; Nelson, Hall & Walsh-Bowers, 1995; Nelson, Walsh-Bowers, Hall & Wilshire, 1994; Nelson, Wiltshire, Hall, Peirson & Walsh-Bowers, 1995) found that consumers living in group homes and supportive apartments had more positive changes in terms of personal growth, had more resident control, levels of personal empowerment, improvements in health and well-being, and community involvement when compared to board and care residents. One study (Hadley, McGurrin & Fye, 1993) noted those living in room and board settings had the longest average community tenure when compared to consumers living in group homes.

While numerous consumers, as adults, had lived at their parent's home for some duration of time, none indicated that living there was what they desired. These data are consonant with Hatfield's (1992) research. She focused on family members' views about preferred living arrangements for family members with a mental illness and found only three percent felt that the family home was appropriate. This study though found that sometimes consumers were forced to move back to the family home because they had no alternatives in terms of a place to live. In some instances, they were returning to an abusive family situation since they lacked any other options for a place to live. Numerous respondents relied on family for support, consistent with the findings from Morrissey and Este's (1997) study.

Participants indicated a need for assistance in finding housing which is supported by Keck (1990). This respondents in my research strongly suggested there was a need for an agency that offered a central registry of housing so that consumers could look for housing from one central location.

One area not addressed in the literature but supported from the data in this study was that consumers wanted assistance when moving to new residences. Consumers found moving particularly stressful and many could not deal with a move effectively. They indicated they needed help in packing and unpacking their belongings, securing a moving truck, financial assistance related to the whole move, and help cleaning the place they were moving from.

Although consumers pointed out that they wanted to live on their own, very few noted privacy as the reason for this, a result that differed from other research (Linney, Arns, Chinman & Frank, 1995; Nelson, Hall & Walsh-Bowers, 1998; Massey & Wu, 1993). Possibly, the issue of privacy was embedded in specific research questions asked by these other researchers. In this study, the desire to be independent and also autonomous in decisions regarding where to live, were the more compelling reasons for residing alone in their own home.

Having choices regarding a number of components of living independently, a good location, and services close by were all major factors related to living on their own, as noted by these research respondents. This data coincide with that identified by the consumers' surveyed by Massey and Wu (1993) as the most important characteristics of desirable living. However, case managers participating in Massey and Wu's research study rated these factors as less important than did consumers. Linney, Arns, Chinman, and Frank's (1995) research also supports what consumers in this research study said about these dimensions. When these researchers surveyed community care operators, in the same study, they viewed these factors as less important than consumers did. From

these studies it is clear that consumers' ideas differ from service providers regarding important dimensions of independent living.

Supports Literature

This study's findings support the conceptualizations put forth by numerous authors (Carling, 1995; Trainor, Pomeroy & Pape, 1993; Wilson, 1989) about the various components desired in a system of support services to address consumer needs (Hammaker, 1996; Marsh, Koeske, Schmidt, Martz & Redpath, 1997). Consumers wanted broad-based supports in areas such as crisis services, legal services, employment services, educational services and leisure services, to name a few, and more informal supports from family and friends. The research undertaken by the researchers above placed mental health consumers at the centre of any services offered and this study's findings support this notion. Consumers wanted services to be individualized and client-centered.

Although the literature notes that a comprehensive support service system includes a number of dimensions, a dearth of information was evident that related to the legal area, employment and education. In this study, consumers indicated that recognition of their unique difficulties with the criminal justice system must be made along with an acknowledgement of their problems in the area of family legal matters. Legal services to address these concerns must be pursued and relationships developed between the criminal justice system and the mental health system to better serve consumers. These findings point out mental health consumers issues related to obtaining an education and appropriate employment while contending with a mental illness. The

need for accommodations to be made and assistance provided, particularly at the post-secondary level and in the workplace was strongly suggested.

The issue of staff control when offering services, noted by several authors (McCarthy & Nelson, 1991; Nelson, Hall & Walsh-Bowers, 1999), in their research, was also consistent with these findings. Consumers regularly objected to receiving services when the staff displayed controlling behaviours (e.g., staff telling the consumer how much food they could eat at a meal), they found this highly undesirable, and in some instances they discontinued receiving services for this reason. Although staff control was somewhat different in the other studies, (McCarthy & Nelson; Nelson, Hall & Walsh-Bowers, 1997), in that they related to resident satisfaction with privacy, decision-making and personal empowerment, they did find staff control inversely correlated to supported housing resident's satisfaction with privacy and personal empowerment. In this study, consumers had experienced controlling behaviour on the part of a variety of professionals including physicians and in both hospital and community settings.

Unique to this study, were the findings related to qualities consumers desired in the staff that were working with them. Caring, compassionate, supportive staff, who were good listeners, were seen as paramount in a consumer's recovery process and whether consumers would even attend appointments to receive services.

Consumers identified the importance of having relationships in their lives both for support and company, and that having relationships enhanced their quality of life. Many consumers were isolated and lonely. Respondents testified to being abused in some of their personal relationships by family and friends. These findings are consistent with

those of Nelson, Wiltshire, Hall, Peirson and Walsh-Bowers (1995) where positive emotional support and emotional abuse were related to quality of life.

This study's findings support other studies of supportive housing where appropriate and adequate supports were factors in reduced hospitalization and community tenure (Hadley, McGurkin & Fye, 1993; Aubry, Tefft & Currie, 1995; Rimmerman, Finn, Schnee & Klein, 1992) and quality of life (George, 1995). Respondents indicated more stability in their mental health and living situation when they received services while residing in the community and that this was paramount to enjoying good mental health.

Gill, Pratt and Librera's (1998) examination of service provision evaluation studies indicated that consumers were almost uniformly positive in their ratings of a service, regardless of the quality of the service. Their study suggested that who administered the rating tool was a factor in the results. Yet in this study, nearly all the research respondents indicated dissatisfaction with various components of services they had obtained even though the researcher conducting the interviews was not a consumer.

The issue of poverty and the need for a more adequate income for consumers was a major research finding in this study. Srebniak, Livingston, Gordon and King's (1995) research is consistent with this finding and they concluded that policy changes to meet the financial realities of community living be addressed.

Unique to this study was the respondents' indicated need for a short-term community crisis stabilization centre when they were experiencing a deterioration in their mental health. They envisioned this centre as having beds, open 24 hours a day, and staffed with highly skilled professionals that could provide them with the services they required so that they would not need a hospital admission.

Finally, this study's findings suggest that the organizations that provide housing and those offering mental health services must work closely together and coordinate their efforts. The position of other authors and researchers (Aviram, 1990; Carling, 1993; Cohen & Somers, 1990, Diamond, 1993; Knisley & Fleming, 1993; Stroul, 1989; Tanzman, 1993, Trainor, Pomeroy & Pape, 1993; Wilson, 1989) support this finding.

Implications for Mental Health Policy/Programs

Given that one in five Canadians will experience a significant mental health problem in their lifetime (Canadian Mental Association, 1999), and that mental illness also impacts one's family and others, understanding and responding effectively to the mental health needs of individuals is imperative. The issues involved in doing so, though, are difficult and complex, and effective solutions are a challenge.

Policy and program development do not occur in a vacuum but rather evolve in an external environment that takes into account factors and influences that are political, economic, pressure-group driven, stakeholder driven and value-based. It is commonly recognized, though, that the political factors have the most profound influence on social policy (Chappell, 1997; Turner, 1999; Turner & Turner, 1995).

In many ways, these research findings have provided a critique of the housing and supports, and the mental health system in place today in Alberta. Although some findings were positive and support current policy and programs, many were not. What are the implications of this research in the development of a plan for housing and supports, a plan that shows some foresight?

The articulation of a contemporary mental health plan for the province, as we enter the millennium, is imperative. While historically many designs have been on the

drawing table, this seems to be where they remained. A mental health blueprint, consistent with the ideas of best practices, that emphasizes a comprehensive community mental health system, funded appropriately, and realized, is essential.

Consumers spoke loudly and clearly that what was needed was a mental health system that was adequately funded. Many respondents in this study experienced extensive waiting lists for housing and mental health services, and lack of services. In today's environment, our current government has remained steadfast that no new monies for mental health will be forthcoming. And yet, it is naive to think that the erosion of health dollars in this province does not come without negative consequences. While an infusion of new dollars into mental health is the most desirable, and strong advocacy to realize this end is encouraged, what we are left with in the interim, is utilizing the current mental health budget in a different way.

To date, the largest portion of the provincial mental health budget resides with the institutions, both at the mental hospitals and with psychiatric units at acute care hospitals (Alberta Health, 1998; Canadian Mental Health Association, Division, 1998; Provincial Health Council of Alberta, 1998; Provincial Mental Health Board, 1995). Moving financial resources from the institutional sector to a comprehensive community-based mental health system is long overdue and decidedly beneficial for Albertans suffering with mental illnesses. This would provide resources required to enhance programs and services already offered but as well assist in establishing innovative programs, such as a community crisis centre, to help consumers live more effectively in the community.

Alberta's mental health system is firmly grounded in the medical model and physician controlled. A system that recognizes that the factors causing, and those

involved in recovering, from a mental illnesses are much broader than one theoretical orientation and what one profession can provide must be not only acknowledged and considered, but put into practice with the appropriate resources. The importance of having housing and offering an array of support services for good mental health, in tandem with psychiatric intervention including the use of medication, must be understood.

Meaningful collaboration amongst all stakeholders is required. In the process, the role mental health consumers can play in the system, must be emphasized and supported. That not all the work needs to be undertaken by professionals is reflected in the recent trend of paying consumers to assist people with mental health problems. Support and advocacy, along with involvement in social policy development are three roles consumers are well suited to undertake.

There must be increased efforts to recruit more professionals such as psychiatrists and mental health trained social workers, psychologists and nurses to work with this population. In conjunction with this idea must be the recognition that with the strain on health care dollars, the mental health consumers living in the community have more serious problems and require skilled professionals to work with them. Some of this work just cannot effectively be undertaken with less trained staff (e.g., paraprofessionals) or a contingent of volunteers. Higher salaries for professionals working in the mental health field should be considered.

The need for permanent, decent, affordable, normal housing in Calgary for mental health consumers, where they also can exercise choices about where they live, was particularly striking. The three levels of government cannot continue to turn a blind eye

to this problem, or set up groups to meet and examine the problem but not take action. There is an urgent and very real need in this area which must be adequately addressed and addressed quickly. In addition, consumers were specific in stating that a supported housing model, while not the answer for every consumer, is a crucial type of housing for consumers. Funding to increase significantly this type of housing must be forthcoming.

Consumers also identified the need for the systems they interface with to work much more closely together. Services were viewed as fragmented and communication between these services was not effective. Witness the number of consumers, who after a period of hospitalization, had no discharge planning, and who were essentially put out onto the streets. Housing organizations, the myriad of mental health services from hospital to community, the criminal justice system, and the financial benefit's arm of Social Services need to link and work collaboratively.

Accessing services was recognized as a major problem for consumers. While an infusion of monies into services so that more professionals can be hired is a partial answer, public funding of private practitioners also needs to occur. Many consumers spoke of their inability to access the services they required from the private sector because they could not afford the costs and yet at the same time, publicly funded services were so backlogged that the consumer had no hope of obtaining what he/she needed.

Expanding hours of service to reflect the realities of consumers who have difficulty with their mental health beyond the daytime hours must be considered. At the same time, services need to be located in consumers' home communities, and many of these services can be the same ones that any Calgary citizen accesses.

The poverty of mental health consumers in this study was profoundly evident and the hardship this resulted in personally was devastating. As well, many indicated that their lack of financial resources, and the stressfulness of coping with this, negatively impacted their mental health. The government must realize that all Albertans need to be treated with dignity and humanity. Adjustments in the financial programs available to provide an acceptable standard of living to those with disadvantages, which means moving individuals out of poverty, is paramount. These programs also must become more flexible and take into account the individual circumstances of recipients

In conjunction with a lack of adequate finances offered by the provincial government, the employment programs available and usually funded by the federal government are falling short of addressing the employment needs of mental health consumers. For those consumers able and wanting work, assistance needs to be provided that paves the way for consumers with employers. On the job help, individualized assistance, promoting job-site accommodations and education to reduce stigma by employers all are necessary for consumers to be meaningful involved in the workforce.

One of the findings of this research study was the prevalence of abuse perpetrated on consumers by staff and families. In this study, 50% of consumers had been abused. In the 1990's, Alberta created Mental Health Advocate legislation, which is in effect today. Unfortunately, despite the alarm raised that the legislation, at the time of development, approval and proclamation, was too narrow in its focus, it was passed in the Legislature. A review of this legislation, with a view to expanding the powers of the Mental Health Advocate, to investigate complaints initiated by consumers who receive services, but who are not necessarily certified patients in designated facilities, should be considered.

Additionally, positions of Patient Right's Advocates, should be developed to serve any consumer receiving a mental health service, and these positions should report to a separate area of government, similar to what the Ombudsman does, so as not to be in a position of conflict of interest.

In any mental health plan, the issue of stigma for mental health consumers needs to be acknowledged and recognized as having profound effects on consumers. Thus increased efforts in the area of community education, starting in the schools at an early age should be considered. In addition, public education aimed at employers and post-secondary institutions should be emphasized.

Finally, the complexity of addressing the etiology and successful interventions of mental illness and the needs of mental health consumers in the process is apparent. Improved funding for research so that answers to many of the mysteries of mental illnesses can be uncovered is required. Until the whole area of mental health is much more fully understood, little progress will be made.

Implications for Social Work Practice

Social work practice has a dual focus on the individual and the environment (Zastrow, 1999). However, most professional education and practice has tended to emphasize working with the individual (McMurtry, 1998). The understanding of the roles that organizations and communities play in the etiology of social problems and directing change efforts at these organizations and communities (macro practice) to address the public issues or to challenge the social order, while always a prerogative of the profession of social work, has rarely been realized or integrated into most social workers' practices (McMurtry). What this has meant then, is the locating of problems

within the individual as opposed to looking at how society is structured for an understanding of social problems. Thus, issues and problems associated with ones gender, race, class, sexual orientation etc. have been individualized and few social workers have challenged the social order.

Mental health consumers have been a group in our society marginalized and their issues only minimally addressed. All too often we have viewed ones mental illness as a problem of the individual and many of our current interventions or treatments have coincided with this view, and focused on “fixing” the consumer. What we have failed to do as a profession is broaden our lens and pursue the second of social work’s functions, namely addressing problems in the external environment that are inexplicably linked to the mental health and functioning of individuals.

Thus the results of this research, help social workers realize that we must address the oppressive features of the environment that impact the mental health of citizens. For example, consumers do not want to be locked up in institutions or shuttled off to institutions to obtain care and services. In fact, what they have told us, is that these places are repressive, regressive and sometimes abusive, and to continue to hold them out as the humane and moral places to treat individuals with mental illness is to close our eyes to these realities. Social workers then can be leaders in advocating for social change in the mental health area and can provide leadership in the social policy arena. Community care, a holistic approach that respects the dignity of consumers, consumer choice and a promotion and enhancement of full citizenship of mental health consumers is attainable.

Secondly, the majority of professionals working with the mentally ill are not social workers, and yet indeed our profession has much to offer (Health & Welfare Canada, 1990). Social workers developing knowledge and skills about mental health problems, their etiology, and the most effective interventions, both at an individual and environmental level will aid those at risk of becoming mentally ill or those already afflicted with mental health problems.

Social workers can also reconsider their professional practice in light of consumers wanting input into decisions that effect them. While professional groups possess expertise and with this, certain power, consumers have said they also have expertise in that they have the first-hand knowledge about the experience of mental illness and the mental health system. What consumers have also indicated is that the system and helpers have not always been helpful or kind, and that their experiences and preferences can and do differ from perspectives of the professionals. While client self-determination has always been an important value held by our profession, more emphasis on seriously putting it into practice as opposed to just talking about it must be undertaken. Social workers need to listen and work much more collaboratively with consumers, and provide information to them, in a way that they can understand. A recognition that no one group has all the answers to addressing mental illness, and a shared approach that minimizes the power differential is desirable and likely more effective.

An interesting implication of these research findings for social workers had to do with the notions of caring, compassion, support and hopefulness. While consumers wanted their professionals knowledgeable and skilled, they emphasized that workers that displayed the above qualities plus the ability to listen well were more highly regarded by

them and more helpful in dealing with their mental health problems. Social work practitioners need to take note of these findings and incorporate these qualities into their practice or if they are already there, be vigilant in their practice to ensure these qualities remain in the forefront.

One of the concerns of consumers was contending with so many different workers and how when workers changed, for the consumer, this was often frustrating and anxiety-provoking. Social workers employed in administrative positions need to listen to these concerns. Ways to deal with caseload structuring so as to minimize disruption to the consumer and compensation issues, whether that be financial matters or professional development, that would encourage workers to work in one area of practice for longer periods of time, must be considered.

Implications for Education and Training

One of the major ways social work is different from other helping professions is its emphasis on the person-in-environment (Zastrow, 1999). Human problems are viewed as having to do with an individual's relationship and interaction with the external world (McMurtry, 1998). In conjunction with the person-in-environment focus, progressive social work has shifted to a structural approach, where the social order is questioned and the oppressive features of the external environment (e.g., ageism, sexism, racism, heterosexism) are considered the primary causes of human problems (McKay, 1999).

While the person-in-environment focus has been the foundation of social work practice and the structural approach more recent, social work education often has emphasized working with the individual and has paid less attention to social work practice at the macro level. Indeed, many social work students also have seen themselves

preparing to strictly practice with individuals and families (McMurtry, 1998). In order to influence the external environment and create meaningful change for mental health consumers and others, a much more concerted effort in social work curricula must be taken to address this end.

Consumers in this study were vocal regarding the importance of professionals that were caring, compassionate and supportive and who displayed good listening skills in the consumers' recovery process. Although it is commonplace in social work curricula to cover these topics, more must be done. Perhaps one place to start is by examining the entrance criteria at schools of social work. While academic performance is usually integral when considering applications to a faculty of social work, there seems to be limited attention given to an individual's personality traits and helping abilities. Those personal qualities conducive to effective social work practice and a means to assess these personal qualities at the time of entry should be developed. Even though students can develop and enhance these qualities during the time of their professional education, a more concerted emphasis on evolving and expanding these qualities and skills, and tools to evaluate if students have them before graduating is essential.

One theme emerging in this study related to client rights, clients having input into decisions that effect them, clients having good information on which to make decisions, and clients having meaningful choices. By virtue of the socialization process involved in professional education, and with increased knowledge and skills, social workers gain power resulting in a power differential that exists between the social worker and the client. Many social work positions are those where the workers can exercise power over clients and it is not difficult to start thinking that the social worker knows best.

Professional education must focus on that ever-important value of client self-determination and the ways for this value to be effectively put into practice.

When examining the cohort of professionals working in the mental health field, the numbers of social workers is significantly fewer than those of other professionals groups (Health & Welfare, Canada, 1990). In one study, when social work students were surveyed, they rated the chronically mentally ill as the least desirable group of clients to work with (Castanuela, 1994). And yet, the need for using social worker's knowledge and expertise with this client population is imperative. Often schools of social work have few to no course offerings related to the mental health field, partly because their faculty does not have interest or expertise in the mental health area (Castaneula). The subtext then, is that social workers do not or need not work with this client population. Hiring faculty with an interest and expertise in the mental health area, and developing course offerings at both an introductory and advanced level must be stressed and intensified.

There is a beginning acknowledgement that mental health consumers have experiences with mental health problems and the mental health system that in some ways make them "experts". Indeed, the results of this study show that some of the best support and help for consumers has come from other consumers. Encouraging them to work in the mental health field is important. However, because many have had significant disruptions in their work history because of their mental illnesses, training to help both them and employing agencies utilize their knowledge and skills in the most beneficial ways to other consumers is necessary and needs to be developed.

Recommendations for Future Research

When conducting the analysis of this research study, a number of major findings emerged. While these findings shed light on the state of housing, supports and mental health services in Alberta, they also help in pointing to future directions for further research. No one study provides all the answers and each piece of research can help us understand the particular phenomena under study a little more thoroughly.

Regarding the research methodology, perhaps further research in this area could include more varied research respondents. Data collected from participants who are more senior in age, who are working, who do receive a decent income, who own their own homes or who are registered at a post-secondary institution may uncover different experiences and preferences regarding housing and supports.

With social agencies beginning to hire mental health consumers and with consumers identifying that other consumers are helpful to them, and sometimes more helpful than professionals, now is a good time to explore this area further. Research that examines who the key helpers are in an individual's recovery process, and what roles and/or tasks each undertakes that are valuable, warrants investigation.

This research indicated consumers' concerns regarding dealing with the legal system and some of the effects current laws, policies and practices have on them. The issue of people with mental illness in conflict with the law, and those requiring assistance in contending with legal matters has had little attention paid to it. Research to begin to identify the major issues consumers are dealing with related to legal matters should be pursued so that appropriate policy and program recommendations can be made.

Alberta's history in working with the mentally ill has always had a strong focus on institutional care. Indeed, governments historically and currently, have not had the political will to undertake mental health reform that emphasizes community mental health care. Research studies that compare institutional and community care in relation to variables such as recovery, quality of life, success of interventions, size and location of care facility, community reinvestment, cost and family relations are required.

Although some studies regarding consumers' preferences in the realms of housing and support have been undertaken, for the most part these were quantitative studies. This study was qualitative. What would provide further understanding would be future research that combines both research designs.

One theme from this research related to a need for a short-term crisis setting where consumers could stay for a few days while their situation and mental health became stabilized. Research that compares the effectiveness of this model of care during a crisis as compared to hospitalization or staying in ones own home would illuminate which was most effective in assisting consumers at a time of crisis.

Studies that examine the relationship between poverty and mental illness must be undertaken. For too long, politically in this province, we have believed that social assistance programs are a handout, not an investment in Alberta citizens, and thus have supported the bare minimum of financial rates for those who need assistance. Solid research that looks at income and considers variables such as rehospitalization rates, frequency of symptomatology and decompensation, quality of life, and recovery can inform our government on its financial assistance policies.

Consumers identified issues regarding housing and moving from one home to another. Comparative studies that examine types of housing, quality of housing and moving, and their relationship to mental health and quality of life would be beneficial.

Many of the participants in this study, while wanting to work, felt hopeless that this would be an option for them. However, they also noted a lack of employment services that addressed their needs in the workplace. Future studies could measure the effectiveness of employment services in assisting consumers in obtaining meaningful employment and keeping it.

Finally, research that focuses on identifying the dimensions of housing and supports that positively impact an individual's state of mental health are necessary. It would seem likely that there is a connection between the an individual's mental health difficulties and their external environments. The continuation of offering services and programs must be based on research that demonstrates their effectiveness and an understanding of the reasons for the resulting positive impact on participating consumers.

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APPENDIX A

Study Consent Form

UNSPOKEN VOICES: THE EXPERIENCES AND PREFERENCES OF ADULT MENTAL HEALTH CONSUMERS REGARDING HOUSING AND SUPPORTS

PARTICIPATION CONSENT FORM

My name is Rita Grenville and I am doing research for my university studies. This consent form, a copy of which has been given to you, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Please take the time to read this form carefully and to understand any accompanying information.

In the past, mental health consumers have had little input into the mental health system. Usually the mental health professionals have decided what is best for consumers. The purpose of my study is to find out what mental health consumers have to say about their experiences and preferences related to housing and support services. While it is hoped that changes in the mental health system will result from your input, there is no guarantee that you or other mental health consumers will benefit.

With your permission, the interview will be audiotaped. Only the research assistants and the principle researcher will have access to the taped material. Every effort will be made to keep your individual answers completely anonymous and confidential and your name will not be used. However, some of your individual responses may be very unique.

If excerpts of your interview are included in the project write-up, people, who have access to the study results, may recognize where certain information came from.

Please indicate now as to whether parts of you interview can be cited in the research project write-up.

I am willing to have parts of my interview cited in the research project write-up:

Yes _____

No _____

Your answers will be put together with the answers of all the other consumers that are interviewed. The researcher will store the research data in a secure place for a period of five years.

Your participation in this study is completely voluntary and you do not have to answer any question that you do not wish to answer. Participation or non-participation in this study in no way will affect services you are or may wish to receive from this agency.

It is my intention to publish the results of this study and potentially publish some other papers that result from this study. However, no personally identifying information, other than what has already been mentioned, will be included in either the study or the publications.

Please indicate now if you would like access to a copy of the study.

YES, I WOULD LIKE ACCESS TO A COPY OF THE STUDY WHEN IT IS COMPLETED _____

NAME: _____

ADDRESS: _____

PHONE NUMBER: _____

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. If you have further questions concerning matters related to this research, please contact me at 240-6441 or my dissertation Chair, Dr. David Este, Faculty of Social Work, University of Calgary at 220-7309.

(Please print)

STUDY CODE NUMBER: _____

NAME: _____

DATE: _____

SIGNATURE: _____

RESEARCHER: RITA GRENVILLE, Doctoral Candidate

Faculty of Social Work, University of Calgary

240-6441