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THE LIVED EXPERIENCE OF PEOPLE RECEIVING ASSERTIVE COMMUNITY TREATMENT: A PHENOMENOLOGICAL STUDY

"...the best way to learn is by discovering a
new knowledge base in partnership
with people with disabilities..."
(Carling, 1995, p. 35)

by

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THESIS

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ABSTRACT

In recent years the Assertive Community Treatment (ACT) model of service delivery, which has held considerable influence in policy and decision making in the mental health field over the past 30 years, has recently been promoted at the provincial policy level in Ontario. Previous studies on ACT have been primarily quantitative in nature and have contributed greatly to the body of knowledge that we now possess regarding the clinical outcomes produced by the ACT model. However, with the Ontario government's financial plan to significantly increase the number of ACT programs in this province, the mental health field would benefit from the added knowledge of subjective experience that is made available through the use of qualitative methodologies. In this study, five ACT clients shared their personal experiences of receiving ACT services in order to answer the question: how do clients experience Assertive Community Treatment? The findings from this study suggest: (a) participants experience ACT as a single relationship that exists between themselves and their case manager; (b) participants experience a need to formulate goals that addressed higher order needs such as independent employment, increased self-esteem, increased income and community integration; (c) participants experience the interaction with and acceptance by non-consumer / survivors as the most important aspect of community integration. The knowledge and understanding of the experiences of ACT clients provided by this study hold important social and professional implications for both ACT and the larger mental health system.

DEDICATION

I wish to thank and dedicate this thesis to my husband, Neil Hopkins.

The faith that you have in me is what enables me to believe in myself.

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This work would not exist without the voices of the participants who agreed to take part in this study. To all of the individuals who shared their personal stories with me, I extend a very sincere "Thank You". Also. a very special "Thank You" to the members of my advisory group, Tess Gahlinger and Geoff Wing. The effort that you put toward this project has added enormously to the validity and reliability of this study.

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LANGUAGE

Language is always an issue that we need to think very carefully about when discussing marginalised groups of any sort. When discussing individuals with psychiatric disorders it is important that language reflect individuals first and foremost, not illness. In this study I have chosen to use several terms to refer to individuals who have been diagnosed with a psychiatric disorder. First, I have chosen to use the term "consumer / survivor" for the simple reason that this is how the majority of the participants in my study referred to themselves. I have also used the term "individuals with psychiatric disorders", a term endorsed by the International Association of Psychiatric Rehabilitation Services (IAPSRS) to be a preferred term. I would like to note, however, that when speaking of the roles that exist within ACT, I have used the terms "case manager" and "client". Much literature has been written regarding the offensive nature of these terms to consumer / survivors (Carling, 1995). These terms unfortunately label one party as somehow dependent on another. In using these terms, however, I am attempting to describe a role (not a person) that exists within the structure of the ACT model. I feel that it is important to be very clear about these roles in order to ensure that the experiences presented are not misconstrued in anyway. It would be problematic, for example, to use the term "consumer / survivors" to refer to those individuals in the role of "clients", as many ACT teams now hire consumer / survivors as staff persons. Likewise, the term "case manager" communicates that the role of the individual involves primary care for the particular participant in question. For example, a client of an ACT team may have many 'workers' but only one person has been assigned the role of the “case manager.” I believe that it is absolutely imperative that language be used in a way that is respectful of people. Concurrently, however, I also believe that in order to have a clear discussion of ACT the most appropriate terms to use, although unfortunate on a personal level, are those that are universally used to describe the specific roles involved.

CHAPTER I

Introduction and Statement of Topic

Overview

Although it has been in practice since 1970, the Assertive Community Treatment (ACT) model has received renewed interest from the mental health field. In recent years special issue publications such as those found in the Administration and Policy in Mental Health, 25(2), 1997, and the American Journal of Orthopsychiatry, 68(2), 1998, provide overviews of past research on ACT and outline current research being done in the area. The designation of ACT as the most effective service delivery model for community treatment in the U.S. by the National Alliance for the Mentally Ill (NAMI) in 1996, indicates a growing recognition of the ACT model by the mental health field. In Canada, the Ontario Ministry of Health has recently endorsed ACT as the service delivery model of choice (Health Systems Research Unit, Clarke Institute of Psychiatry, 1998) and has provided 11.8 million dollars in funding to establish 21 community-based teams that will provide services for up to 1,650 people with psychiatric disorders of a severe nature (Ontario Ministry of Health, 1998). Research into ACT has typically been quantitative; an attempt has been made to objectively measure the clinical affects of these programs on individuals with psychiatric disorders. These studies have consistently found that a significant number of individuals who receive ACT services experience lower re-hospitalisation rates and greater symptom stabilisation than individuals receiving similar services (Burns & Santos, 1995; Mueser, Bond, Drake &

Resnick, 1998; Olfson, 1990). Despite the success of the ACT model in these areas, however, many individuals in the mental health field, including psychiatric consumer / survivors, have criticised the ACT model for being a product of the biomedical approach (Carling, 1995; Mueser et al., 1998; Nugent & Spindel, 1998). These criticisms of the ACT model stem from the apparent emphasis that is placed on treatment and medication management over and above psychosocial and rehabilitative services. According to a description of ACT by Drake and Burns (1995), ACT services are "analogous to care in a hospital" (p.667). The focus on symptom reduction through the promotion of medication compliance, and the primary importance placed on the role of the psychiatrist, raises concerns regarding the consequent de-emphasis on community involvement, family and community-building (Nugent & Spindel, 1998).

The gap between the medical effectiveness of ACT (in terms of decreased hospitalisation and symptomatology) and the apparent lack of focus on psychosocial aspects of care (such as community integration) has created a divide within the mental health community. Proponents of the ACT model (primarily mental health service providers and family members) argue that individuals with psychiatric disorders are able to maintain lives in the community primarily as a result of the assertive attention that has been paid to medication compliance and symptom management. Opponents of the ACT model (primarily academics and psychiatric consumer / survivors) argue that the entrenchment in medical philosophy and the lack of a more prominent focus on psychosocial aspects of rehabilitation render the ACT model unable to truly empower and integrate clients into the community.

Both the research that examines clinical outcomes of ACT and the research that critiques it are missing one essential ingredient, the subjective experience of the ACT client. Although much of the literature that critiques ACT has been contributed to in some form by psychiatric consumer / survivors, these are not individuals who were currently receiving ACT services at the time that the research was conducted. The voice of the ACT client is a critical missing element in the currently available body of knowledge regarding ACT. Rather than conduct research that simply adds fuel to the debate, it would be more helpful to try to understand the meaning that clients attribute to their experience within the ACT program.

An alternative way of researching ACT, which might help us to understand it more fully, is to acknowledge that each individual experiences the ACT program differently and each experience will mean something different to each client. To gain an understanding of the clients' experiences, educators and researchers should invite the clients to talk about their experiences with the ACT program. By exploring the experience of clients, insights will be uncovered that will provide meaning and understanding. This knowledge will help guide service providers, researchers and health planners to ensure that the services offered by ACT are based upon a deeper understanding of the meaning of the ACT experience for clients.

One way to begin to truly understand the experiences of the ACT clients is to ask the question: how do clients experience Assertive Community Treatment? This question has guided the focus and choice of methodology for this study. A heightened understanding of clients' experiences can offer an essential piece to the discussion of

ACT both in terms of service provision and policy decision-making.

Personal Interest in Pursuing This Research

An important premise of the phenomenological approach is the concept of *epoch*, wherein "the researcher brackets his or her own preconceived ideas about the phenomenon to understand it through the voices of the informants" (Field & Morse, in Creswell, p. 54, 1998). In my research the issue that I am reflecting on is ACT. My own perspectives on ACT have been affected by two contradictory experiences. On the one hand, my first employment experience in my field was as a service-provider in a hospital-based ACT program. Although I was employed on a contractual basis and only held the position for 6 months, I was greatly influenced by the program, my colleagues and the general program philosophy. In my opinion the general philosophy held by program staff and many clients was that the ACT program had been instrumental in providing opportunities for individuals who had been diagnosed with severe and persistent mental illness to live in the community.

Many of the clients from this program had been institutionalised for approximately 10-15 years, in some cases for as long as 20 years. As a service-provider one of my roles was to co-facilitate a "recovery group." This was a 16 session discussion group based on the Recovery Handbook (Spaniol, Koehler & Hutchinson, 1995) that was facilitated by myself and another ACT service provider with 12 ACT clients. A main component of this recovery group was to have clients reflect upon their own recovery and what it meant to them. I was always struck by the stories of empowerment that accompanied the recovery of individuals who had been institutionalised for extremely long periods of time. For many of these individuals family contact no longer existed (either because family members were deceased or because too many bridges had been burnt); they possessed little knowledge of daily living skills (most likely attributed to long-term institutionalisation); and they were very apprehensive about leaving hospital grounds and venturing into the larger community (again likely attributed to long-term institutionalisation). To listen to the stories of hope and fulfilment that many of these clients attributed to entering the community with the help of the ACT team was an inspiration to me.

After this contract position was complete I decided to pursue an MA degree in community psychology. Community psychology is the study and application of psychology for the purpose of bettering the lives and experiences of marginalized people. As Walsh-Bowers (1998) states in his review of the history of community psychology in Canada:

> community psychology is the applied subdiscipline [of psychology] that is explicitly oriented to developing applications of psychological theory, values, and research for the purposes of preventing social, economic, health, and mental health problems; improving the quality of life and well-being, particularly for marginalized groups; and building the sense and reality of community and empowerment (Walsh-Bowers, 1998, p. 282).

Community psychology is based heavily in the values of caring and compassion, health, self-determination, human diversity, and social justice (Prilleltensky & Nelson,

1997) and is framed within an action-oriented approach. When applied to the mental health field, community psychology is concerned with improving the quality of life of psychiatric consumer / survivors through community support and social action.

During my studies in community psychology many of my previous thoughts and philosophies with regard to the mental health system were challenged. When community psychology values are applied to the ACT model many questions arise as to whether or not the services provided by ACT promote empowerment, self - determination and social justice for psychiatric consumer / survivors. It is considered that ACT follows a medical model approach to service that does not provide the independence and community integration that is needed by all individuals. Questions therefore arise as to whether or not ACT teams inadvertently isolate clients from the very communities that they try to integrate them with. The question arises as to whether ACT teams concentrate too much on clinical issues, such as medications and symptomatology, and not enough on including rehabilitative and social services such as vocational, educational and social support.

During my first year of the community psychology program I had the opportunity to listen to Diana Capponi, a psychiatric consumer / advocate speak about her thoughts on ACT. She expressed that from her view point the ACT model provided too many services for clients which in turn impinged upon the client's independence and ultimately their ability to be empowered. Additionally, Diana expressed concern that the ACT model promotes an in vivo approach that ensures that all services are provided by the team and hence interferes with true community integration; in other words clients are *in* the community but not *a part of* the community. I felt myself caught between my previous experience as a service-provider with an ACT team and what I was learning as a student of community psychology. Many questions came to mind; What about the individuals who I had heard express such feelings of empowerment as a result of being integrated into the community by an ACT team? Had they not really been empowered but only thought so? Could they have been more empowered? Was there an alternative way for individuals who had been institutionalised for up to 20 years to rejoin the community? And ultimately – was ACT a reprehensible model that only served to disempower and restrain psychiatric consumer / survivors *or* was ACT a necessary initial step in the recovery of individuals who had been institutionalised on a long-term basis? In my quest to determine where I stood on the issue of ACT, it occurred to me that there was a very important piece of information that I was missing – what do the clients think? I felt that I could not formulate a truly informed opinion on ACT without first accessing the subjective experience of ACT clients. I also felt that it was important to add the stories of ACT clients to the existing knowledge of ACT in order to facilitate a broader and more comprehensive discussion of the model.

I have made this thesis, therefore, my quest to access the voices and stories of ACT clients. In the process I also hope to put to rest some of my own questions and dilemmas with regard to the issue of ACT.

CHAPTER II

Review of Relevant Literature

Assertive Community Treatment

In this chapter I present the historical development of ACT as well as the premises for each side of the debate regarding its efficacy. I also review the values and assumptions associated with three paradigms in mental health (Carling, 1995) in order to situate each of the arguments within a larger philosophical context.

Historical Background

In order to acquire an understanding of ACT, it is first helpful to review the historical context that preceded and surrounded the development of this model. The deinstitutionalisation of individuals with psychiatric disorder, that began in the 1950's and still continues today, transferred the care of institutionalised individuals from the psychiatric hospitals to the community (Mechanic & Rochefort, 1990). The early years of deinstitutionalisation were characterised by inadequate care and housing, undue family burden and neglect of the rights of individuals with mental illness (Mechanic & Rochefort, 1990; Mowbray, Collins, Plum, Masterton & Mulder, 1997). Many individuals who had once been institutionalised had difficulty negotiating their way around the often fragmented social service system that existed in the community. According to a study by Mechanic (1991), the majority of individuals who had been previously institutionalised lacked initiative and possessed a limited ability to advocate on their own behalf. Consequently, many individuals with severe psychiatric disorder experienced great difficulty in accessing community-based services such as public transportation, financial services and community housing. As a result of their inability to cope with aspects of daily living, the majority of individuals experienced high re-hospitalisation rates and often functioned poorly between hospital admissions (Mechanic & Rochefort, 1990; Stein, Test & Marx, 1975).

In order to increase the likelihood of success for individuals with psychiatric disorders in the community, much effort was put into developing models of service-delivery that would assist individuals with daily living skills as well as treatment (Test, 1981). The ultimate aim of these models was to provide intensive support to help consumer / survivors maintain their lives in the community (Test, 1992).

The TCL Model

The most prominent service delivery model was the Training in Community Living (TCL) model developed by Stein, Test and associates in 1970. The TCL model was first described by Marx, Test and Stein (1973) as an alternative to hospital treatment that focused on providing patients with the coping skills and independence required to maintain their lives in the community.

The original TCL model was comprised of 61 former inpatients of the Mendota State Hospital who were determined to be at risk for repeated hospitalisations (Marx et al., 1973). All 61 former patients of the hospital were placed into the community and linked with TCL staff who provided services focused on the acquisition of skills that were necessary to live in the community. All of the treatment services were provided in the community. A particular emphasis was placed upon not re-hospitalising anyone who was being managed in the community if at all possible. Staff were required to relate to clients as responsible individuals and to develop close working relationships with other community agencies.

Clients lived in a variety of places within the community including the local YMCA, YWCA, hotels, apartments and boarding houses. The treatment provided by the TCL program consisted of a "full schedule" of daily living activities in the community which included ongoing pharmacotherapy (Marx et al., 1973). Marx et al. (1973) describe the support provided by staff as "motivating, supporting, and often being by patients' sides day and evening" (Marx et al., 1973, p. 506). Vocationally, clients received intensive assistance in locating jobs in the community or in sheltered workshops. Staff are described as being in daily contact with clients and their job supervisors in order to aid with on the job problems. Assistance with activities of daily living usually addressed such things as laundry, house cleaning, shopping, cooking, grooming, budgeting and the use of public transportation. Marx et al. (1973) describe the frequency of client-staff interaction as "daily, even hourly, contact of staff with patients" which was "gradually diminished based on each patient's progress in the treatment program" (Marx et al., 1973, p. 506).

Two individual studies were performed on the original TCL model (Marx et al., 1973; Test & Stein, 1978). The first study performed by Marx et al.(1973) involved 61 inpatient clients at Mendota State hospital who, at the time of the study, had been hospitalised between 3 and 18 months. Each of the 61 participants had been determined by hospital staff as being "not currently capable of sustained community living" (Marx et al., 1973, p. 506).

Study participants were randomly assigned to either the Training in Community Living experimental group (Community Treatment Group, CTG, n = 21) or to one of two control groups; the Research Unit Controls Group (RUC, n = 20) or the Other Units Control Group (OUC, n = 20). The RUC group remained in hospital and received inpatient treatment from the same clinicians involved in the CTG group while participants in the OUC group received inpatient treatment from their referring wards. The treatment given to the experimental group is described by Marx et al. (1973):

> Patients were given sustained and intensive assistance in finding a job or sheltered workshop placement .... Patients were aided in the constructive use of leisure time and development of effective socialisation skills by staff prodding and supporting their involvement in relevant community recreational and social activities .... This frequently included staff members accompanying patients to such functions on a regular basis (Marx et al., 1973, p. 506).

The results of this study indicate that after five months of treatment, participants in the experimental group had experienced significantly less time in hospital and more time in semi-sheltered settings than either control group. Additionally, the experimental group achieved higher levels of occupational functioning than controls but did not improve significantly with regard to psychiatric symptomatology.

The second study performed on the TCL model by Test and Stein (1978) was intended as a follow-up to the study by Marx et al. (1973). This study involved 130 study participants randomly assigned to either an experimental group (n = 65) who were assigned directly to the TCL model (never entering hospital) for 14 months before being integrated into existing community agencies or to the control group (n = 65), which received in-hospital treatment for as long as necessary before being linked with appropriate community agencies. Assessment data were collected on study participants at baseline and every 4 months for 28 months. The results of this follow-up study replicated those found by Marx et al., (1973). It was found that participants in the experimental group experienced significantly less time in hospital than the control group. Additionally the experimental group spent significantly less time unemployed and earned significantly more money as a result of full-time competitive employment. It is important to note, however, that no more time was spent by experimental participants in full-time competitive employment than control participants. Of great importance was the finding that study participants in the experimental group experienced significantly reduced psychiatric symptomatology as compared to the control group. Experimental participants were also found to be significantly more satisfied with their life situations than controls at 12 months.

Follow-up results (Stein & Test, 1980) from this study, however, indicated that once experimental participants "graduated" from the TCL program and were receiving solely traditional community programming, gains that had been seen up to the 14 month period began to diminish significantly. There was a gradual increase in hospital use after participants left the program. Time spent in hospital doubled for the experimental group while hospital use by the control group remained stable. There was a steady decline in participation in sheltered workshops, and there was no longer any significant difference between experimental and control participants with regard to social adjustment, satisfaction with life and psychiatric symptomatology (Stein & Test, 1980).

In summary. studies on the original TCL model (see Table 1) indicate that during the time in which subjects actually participate in the program they are significantly more likely to experience decreased hospitalisation and psychiatric symptomatology and increased employment in both sheltered and competitive positions. Results also indicate, however, that once participants are no longer receiving TCL treatment the likelihood of experiencing any of these gains drops significantly.

Table 1

Outcome Findings on TCL

TCL Studies	Study Pop.	Follow up Period	N	Hospitalisation ACT vs. control Group	Symptomatology ACT vs. control group	Vocational function ACT vs. control group	Social function ACT vs. control group	Independent Living ACT vs. control group	Service Satisfaction ACT vs. control group	Quality of Life ACT vs. control group
Marx et al., (1973)	Prior hospitalisation	29 months	61	sig.	ns	sig.	ns	sig.	nr	nr
Stein & Test (1980)	At risk for repeated hospitalisation	12 months	130	sig.	sig.	sig.	ns	sig.	nr	sig.
Test & Stein (1980)	At risk for repeated hospitalisation	28 months	130	ns	ns	ns	ns	ns	nr	ns

nr-not reported, ns-not significant, sig.-significant at $p<.05$, SMI-severely mentally ill

Replications of the TCL Model: Assertive Community Treatment

Fidelity. Many replications of the TCL model have been put into place since the results of the original model were first published. The replication models are referred to as either Programs for Assertive Community Treatment (PACT) or simply Assertive Community Treatment (ACT) teams. According to McGrew, Bond, Dietzen and Salyers (1994), there is great variation in the degree to which these programs replicate the elements of the original TCL model. The degree to which a program adheres to the original model is referred to as fidelity. The study by McGrew et al. (1994), that examined 18 programs using the Index of Fidelity of ACT (IFACT), indicated that "later generation programs differed from earlier generation programs both in terms of lower fidelity (replicated the elements of the original model to a lower degree) and in decreased program impact in reducing days hospitalised" (McGrew et al., 1994, p. 675). In other words, although the replicated programs are based on the model, each program has not been implemented to conform exactly to the original model. Also, the more recent a program has been implemented, the less likely it is to place as large of a focus upon reduction of days in hospital (McGrew et al., 1994). Another major way in which more recently implemented ACT programs differ from the TCL model are with regard to long-term treatment. Many ACT programs now provide non time-limited treatment allowing the clients to stay and receive treatment on an indefinite basis.

Drake and Burns (1995) describe the ACT model as consisting of a multidisciplinary team of support staff which provides continuous, individualised treatment and support for an unlimited period of time. ACT teams purportedly provide all of the supports that are necessary to assist clients in maintaining basic living requirements in a community environment (Mueser et al., 1998).

These services include a range of medical and psychological services, including: assistance in meeting basic financial needs, learning basic living and self-care skills, intensive care programs, outpatient treatment services offering both medications as required and practical problem-solving therapies, adequate residential support and supportive services to family members and other community residents (Bachrach, 1988; Mechanic, 1991; Test, 1981). The focus of these services is concentrated into five major areas: (a) vocational and work related skills, (b) activities of daily living, (c) social and recreational activities, (d) family support and (e) medications, psychotherapy and nursing care (Estroff, 1981).

Ontario guidelines. The Ontario government has recently published guidelines for ACT teams practising in Ontario. These guidelines state that all ACT teams are required to meet the following criteria: (a) staff make-up will be multidisciplinary in nature, including both a psychiatrist and a psychiatric nurse; (b) the team will consist of between 10-12 full time staff, with a staff-consumer ratio of between 1:6 to 1:12; (c) programs will provide assertive outreach that takes place in the environment of the consumer's choice; (d) interventions and services will be provided on an individualised basis; (e) services will be made available 24 hours a day, 7 days per week, 365 days per year; (f) the program will maintain on-going links with existing community services; (g) appropriate monitoring and evaluation mechanisms will be implemented to ensure that program design and intention are met; and (h) the purpose of the team will be to meet the needs of individuals with severe mental illness (Ontario Ministry of Health, 1998).

Review of outcome studies. Over the past two decades the ACT model has become increasingly well known in the field of community mental health. To date over 40 empirical studies regarding ACT exist in the literature (Mueser et al., 1998) and currently practising ACT teams exist in over 30 U.S. states (Deci, Santos, Hiott, Schoenwald & Dias, 1995).

I have chosen to review 19 of the major randomised controlled trials that have been reported on ACT programs up until May 1999 (including the original studies by Marx et al., 1973; Stein & Test, 1980; Test & Stein,1980). Table 2 provides a summary description of these studies. Each study has been reported in terms of the effects of treatment on the experimental group.

The majority of these studies indicate that ACT services result in less time in hospital for clients. Nine out of the 19 studies reviewed reported findings that participants who received ACT services experienced significantly less time in hospital than controls who did not receive ACT services (Bond, Miller, Krumwied & Ward, 1988; Bush, Langford, Rosen & Gott, 1990; Essok & Kontos, 1995; Hoult, Reynolds, Charbonneau-Powis, Weekes & Briggs, 1983; Lehman, Dixon, Kernan, Deforge, Connolly, Muijen, Audini, McNamee & Lawrence, 1997; Marks et al., 1994; Marx et al., 1973; Stein & Test, 1980). Hospitalisation was the one variable most often found to be significant, making it the one consistent finding across studies.

Next to hospitalisation the most reported finding among the 19 studies was a significant increase in independent living for individuals who receive ACT services

(Essok & Kontos, 1995; Lehman et al., 1997; Marx et al., 1973; Morse, Calsyn, Allen, Tempelhoff & Smith, 1992; Morse, Calsyn, Klinkenberg, Trusty, Gerber, Smtih, Tempelhoff, Ahmad, 1997; Stein & Test, 1980). Independent living refers to a "living situation in which the client lives in the community where there is no 'built in' psychosocial support" (Marx et al., 1973, p. 510). ACT clients also experienced significantly decreased symptomatology (Hoult et al., 1983; Marks et al., 1994; Morse et al., 1997; Stein & Test, 1980) and increased satisfaction with services (Chandler, Meisel, McGowen, Mintz & Madison, 1996; Hoult et al., 1983; Marks et al., 1994; Morse et al.. 1992; Morse et al., 1997) in a moderate (4 and 5, respectively) number of the studies.

The majority of studies tested for experimental effects with regard to treatment outcomes, such as hospitalisation, symptomatology and satisfaction with services. It is important to note that psychosocial variables were less likely to be included as indicators in the studies. Only 7 of the 19 studies used vocational functioning as an outcome variable (Bond, McDonel, Miller, Pensec, 1991; Hoult et al., 1983; Marks et al., 1994; Marx et al., 1973; Morse et al., 1997;1982; Stein & Test, 1980). Of these seven studies only two reported any significance for the experimental group with regard to vocational functioning (Marx et al., 1973; Stein & Test, 1980). Both of these studies incorporated specific vocational components into the ACT program. Meuser et al. (1998) suggest that the incidence of vocational significance for programs that incorporate specialised programming may indicate that improvement in vocational functioning is due to the vocational component itself and not to ACT per se.

Social adjustment has been defined as the "quality of social relationships, the ability to meet social role expectations, or social networks" (Mueser et al., 1998, p. 42). The majority of randomised controlled studies that have used social adjustment as an outcome variable have found little to no significant improvement that can be attributable to ACT (Bond et al., 1988; Bond et al., 1991; Chandler et al., 1996; Jerrel & Hu, 1989; Lehman, Herron, Schwartz & Myers, 1993; Lehman et al., 1997; Marx et al., 1973; Morse et al., 1992; Muijen, Cooney, Strathdee, Bell & Hudson, 1994; Solomon & Draine, 1995a; Solomon & Draine 1995b; Stein & Test, 1980). Only three of the studies that incorporated social adjustment as an outcome measure suggested any significant improvement attributable to ACT (Bush et al., 1990; Marks et al., 1994).

Additionally, few studies have focused on quality of life as an outcome of ACT. Mueser (1998) defines quality of life as a "patient's subjective satisfaction with different areas of living such as housing, finances, relationships and health" (Mueser, 1998, p. 42). Of the 10 studies that investigated quality of life (Bond et al., 1988; Chandler et al., 1996; Essok & Kontos, 1995; Hoult et al., 1983; Jerrel & Hu, 1989; Lehman et al., 1997; Solomon & Draine, 1995a; Solomon & Draine, 1995b; Stein & Test, 1980), only four showed any significant improvement in the quality of life of ACT clients (Chandler et al., 1996; Essok & Kontos, 1995; Stein & Test, 1980). Meuser et al. (1998) suggest that these improvements may be more attributable to changes in hospitalisation or housing stability.

In summary, clinical outcomes such as decreased hospitalisation and symptomatology have been found to be fairly consistent findings across randomised controlled trials of

ACT. The majority of the studies reviewed, however, did not incorporate rehabilitative and social supports as experimental outcomes on a consistent basis. This lack of focus on psychosocial services as indicators of ACT success suggests that the individuals researching ACT consider medically-oriented outcomes to be the primary focus of ACT. In accordance with the lack of focus on psychosocial variables experimentally, the fact that few significant effects were found in these areas also suggests a lack of focus in the provision of these types of services by ACT clients.

Table 2

Outcome Findings on ACT

ACT Studies	Study Population	Follow up Period	N	Hospitalisation ACT vs. control group	Symptomatology ACT vs. control Group	Vocational function ACT vs. control group	Social function ACT vs. control group	Independent Living ACT vs. control group	Service Satisfaction ACT vs. control Group	Quality of Life ACT vs. control Group
Hoult et al. (1983)	SMI	1 year	120	sig.	sig.	ns	nr	nr	sig.	ns
Bond et al. (1988)	At risk for repeated hospitalisation	6 mths.	167	sig. (2 centres)	ns	nr	ns	nr	nr	ns
Jerrel & Hu (1989)		2 years	35	ns	ns	nr	ns	nr	nr	ns
Bond et al. (1991)	SMI – substance abuse	18 mths.	97	ns	ns	ns	ns	ns	ns	nr
Bush et al. (1990)	High rate of previous hospitalisation	12 mths.	28	sig.	nr	nr	sig. (by case management judgement)	nr	nr	nr
Morse et al. (1992)	SMI/homeless	12 mths	178	nr	ns	nr	ns	sig.	sig.	nr
Lehman et al. (1993)	Dual Diagnosis	12 mths.	54	ns	ns	nr	ns	nr	nr	nr
Marks et al. (1994)	SMI	20 mths	189	sig.(# of days)	sig (BPRS at 20 mths)	ns	sig. (20 mths)	nr	sig.	nr

Muijen et al. (1994)	High rate of hospitalisation	18 mths	82	ns	ns	nr	ns	nr	ns	nr
Essok & Kontos (1995)	SMI	18 mths	262	sig.	nr	nr	nr	sig.	nr	sig.
Quinlivan et al. (1995)	SMI	2 yrs	90	ns	nr	nr	nr	nr	nr	nr
Solomon & Draine (1995a)	SMI/ homeless/ former inmates	1 year	200	nr	ns	nr	ns	nr	nr	ns
Solomon & Draine (1995b)	SMI/ homeless/ former inmates	5 years	51	nr	ns	nr	ns	nr	nr	ns
Chandler et al. (1996)	SMI	1 year	439	ns	ns	ns	ns	ns	sig.	sig.
Morse et al. (1997)	SMI/ homeless	18 mths.	165	nr	Sig. (over broker model)	ns	nr	sig.	sig.	nr
Lehman et al. (1997)	SMI	1 year	152	sig.	ns	nr	ns	sig.	nr	ns

nr-not reported, ns-not significant, sig.-significant at $p<.05$, SMI-severely mentally ill

Qualitative Studies of ACT

The above reviewed studies of ACT are all quantitative in nature. Although quantitative research on ACT is very beneficial in terms of producing objective, outcome findings, qualitative research can add to the understanding of the experience of ACT for clients. The only published qualitative study on ACT that I am aware of is Sue Estroff's book, Making it Crazy (1981). This study is an ethnographic study that examines the culture in which ACT clients live. Estroff (1981) explains her reasoning for choosing a qualitative approach to the study of consumer / survivors:

> I regard our voyages into the experiential and daily world of the psychotic, the developmentally different, the anxious, depressed, and excited as elementary steps toward an understanding of humanness that encompasses, appreciates, and invites differentness in living, thinking, and feeling rather than excluding, denigrating, and eschewing these individual variations (Estroff, 1981, p.16).

Estroff's two-year study in which she embedded herself in the daily culture of ACT clients, enabled her to "discover the richness and diversity of the clients' world" (Estroff, 1981, p. 249). One of the major findings of Estroff's work was that ACT clients seem to have less control over their time, space and resources than people in the community. However, observations of ACT clients also seemed to indicate that they experienced more control in these areas than individuals who were hospitalised. The ACT clients involved in Estroff's study tended to spend the majority of their time with each other. This phenomenon was attributed to lower income, lack of mobility and decreased accessibility to living space. Estroff's work also drew attention to the lack of sufficient drug-free alternatives as well as lack of encouragement within the mental health system to explore drug-free alternatives. Findings regarding work showed that clients of ACT often faced a "subtle discrimination [by the] community at large." Many employers would not hire clients who they evaluated as employment risks (long histories of unemployment). Co-workers on volunteer jobs would often patronise clients and highlight their deficits. Additionally, alternatives offered by the mental health system were often seen by clients as humiliating and degrading. Of great importance was the finding that the majority of ACT clients, while preferring each other and psychiatric professionals for company, ultimately preferred to be alone. Estroff hypothesised that this may be due to their own perception of differences between themselves and people outside of the ACT team and that clients did not view themselves as "regular" people.

Criticisms of ACT

ACT is often criticised by individuals who consider it to be a product of the bio-medical approach, which therefore, places a primary focus on producing treatment-oriented outcomes, such as reduced hospitalisation and symptomatology. This bio-medical focus can be seen in the many descriptions referring to ACT programs as being "much like hospital-based treatment" (Burns & Santos, 1995, p.669; Marx et al., 1973; Stein & Test, 1980). It is common, for example, for ACT staff to monitor clients' medication intake on a daily basis (Burns & Santos, 1995; Drake & Burns, 1995) and to devote a significant amount of staff time to symptom assessment.

Many critics of the ACT model, including psychiatric consumer / survivors, believe that this entrenchment in the biomedical approach creates a barrier to client empowerment, true community integration and social justice (Carling, 1995). The power differential between the staff and clients of a model that is based in the bio-medical approach becomes very apparent when you consider that mental health providers are viewed as professionals and psychiatric consumer / survivors are viewed as patients or even clients (Carling, 1995). Critics of ACT claim that this power imbalance manifests itself in the form of social control (Nugent & Spindel, 1998). Social control exists when patients or clients are required to comply with medication regimens in order to continue to be eligible for services. Financial management is also a common practice of ACT which socially controls clients by keeping their money in an effort to help them to decide what they should or should not spend their money on. Another form of social control that is cited by critics is the practise of providing continuous "observation" 24 hours a day, seven days per week, 365 days per year. Although these social control practises are seen by proponents of ACT as ways of ensuring health (both physical and mental) and stabilisation for clients in the community (Drake & Burns, 1995; Marx et al., 1973; Stein & Test, 1980), critics of ACT point to the fact that these practices stand in the way of individual rights (Carling, 1995; Nugent & Spindel, 1998).

A second area of concern regarding ACT lies with the scientific literature itself. The concerns lie with both the process used to undertake the studies and the outcome findings that were produced. With regard to process, many of the studies were conducted by non-independent interviewers and in many cases the relationship between the researcher and those being researched is unclear. For example the person collecting the data in many of the studies was the case manager. This causes much concern with regard to bias. Larson, Attkinson, Hargreaves & Nguyen, (1979) emphasise the need to ensure that evaluations of individuals with psychiatric disabilities is not biased toward the perspective of the service provider (see Clark, Scoll & Krupa, 1993 for a more in-depth review of staff introduced bias).

Outcome findings produced by randomised controlled studies on ACT concentrate primarily on hospitalisation and symptomatology as indicators of ACT's success (see Table 1). The small number of studies that have examined psychosocial or rehabilitative outcomes indicate that these are not seen as important aspects for determining ACT success. This finding alone emphasises ACT's concentration on treatment-oriented outcomes, its entrenchment in the medical model and suggests the inability of the model to deal with the whole individual. Of primary concern are the findings that have been produced from the few studies that have examined psychosocial areas such as vocational, educational, and social functioning. These studies have found few to no significant effects for clients (see Table 1). In fact the only effects that have been found for vocational functioning are most likely due to the addition of specialised programming, suggesting that the original guidelines are not sufficient for producing significant effects in this area. According to Mueser et al. (1998), "…if models of intensive community care are to improve the lives of persons with major mental illness, they will have to demonstrate more success than simply helping patients stay out of the hospital" (Mueser et al., 1998, p. 63).

In summary, Nugent and Spindel (1998) describe their thoughts on ACT:

> The PACT model would seem to be a throwback to a time when the rights of those being "treated" were not of much concern to mental health practitioners. The degree to which current mental health workers and administrators are embracing PACT is particularly worrisome for this reason. It points to the absence of a grounding philosophy in community mental health practice, which has at its base, a solid respect for the autonomy and rights of individuals (Nugent & Spindel, 1998, p. 2).

Paradigm Shift

In order to fully understand the ACT debate, it is important to understand the shift in paradigms that has occurred since the conception of ACT. A knowledge of the different paradigms and the values that lie behind each is necessary in order to fully understand the two sides of the debate.

> A paradigm may be viewed as a set of basic beliefs (or metaphysics) that deals with ultimates or first principles. It represents a worldview that defines, for its holder, the nature of the "world," the individual's place in it, and the range of possible relationships to that world and its parts, as, for example, cosmologies and theologies do. The beliefs are basic in the sense that they must be accepted simply on faith (however well argued); there is no way to establish their ultimate truthfulness (Guba & Lincoln, 1994, p. 107).

Carling argues that the field of mental health is currently undergoing a shift in the way that it views individuals with psychiatric disorders or rather a shift in paradigms (Carling, 1995; Ridgeway & Carling 1988; Zipple & Ridgeway, 1990). He contends that the first paradigm commenced during the time of institutionalisation (1930-1950) when individuals with mental illness were looked upon as patients. This paradigm, referred to as the medical model or biomedical approach is characterised by facility-based thinking that focuses exclusively on illness. According to Nelson, Lord and Ochocka (1996) the medical model is entrenched in the values of professionalism, institutionalisation, and places a primary focus on treating illness.

The second paradigm, according to Carling began with the rehabilitation movement (1970-1989) when individuals with mental illness were viewed as service recipients (Carling, 1995). This school of thought was most influential in terms of community planning and mental health policy in the early and mid 1980s (Spaniol, Zipple, Cohen, 1991). This paradigm is viewed by Carling (1995) as a "transitional" period in which individuals with psychiatric disorders were seen primarily in terms of their disabilities and were viewed as service recipients (clients and consumer / survivors). The rehabilitative school of thought developed out of a need for increased community services for individuals with severe mental illness (Anthony & Blanch, 1989). The approach focuses on the provision of community treatment, decreased re-hospitalisation, and life skill development for individuals with severe mental illness (Nelson, Walsh-Bowers & Hall, 1998). Unlike the medical model which focuses primarily on medication, psychosocial rehabilitation recognises the need for support around the development of coping skills (i.e., stress management, interpersonal relations, budgeting). The rehabilitative approach places a greater emphasis on the values of de-professionalism, community orientation, and a focus on psychosocial deficits (Nelson et al., 1996).

Carling (1995) puts forth the notion that a third paradigm has begun to emerge in the 1990s in which individuals with mental illness are seen as citizens with rights to complete community participation and integration (Carling, 1995). This new paradigm emphasises change at both systemic and individual levels (Nelson et al., 1998) that promotes viewing individuals as "citizens who ... share with all citizens the potential for, and right to, full community participation and interaction" (Carling, 1995, p. 31). In practise this approach promotes the use of the community as a resource, the use of supports based on reciprocal relationships, and the centralisation of power around the individual (Carling, 1995). Consistent with this shift, Trainor, Pomeroy and Pape (1993) have developed a framework for the provision of support to individuals with mental illness. The framework emphasises a centralisation of power around the individual and the various groups providing support. Also, equivalent services are provided by consumer groups, family, friends, and generic community groups as well as by mental health professionals. The empowerment-community integration approach promotes the values of informal supports, community integration and a holistic focus on individual strength and potential (Nelson et al., 1996).

By viewing ACT in relation to the various paradigms we can see how the ACT model emerged from the values of the biomedical approach. The emphasis on treatment as seen in the importance placed on outcomes such as decreased hospitalisation rates and psychiatric symptomatology is clearly a product of the illness focused medical paradigm. I would argue, however, that the reduction in emphasis upon decreased days in hospital noted by McGrew et al. (1994) as a fidelity issue for more recently implemented ACT programs, is a reflection of a change in philosophy and possibly an effort to bring the ACT model more in line with a rehabilitative philosophy or approach. The TCL model was implemented in the early 1970's just as the second paradigm was forming. The TCL model therefore, followed the traditional, medical model way of thinking. As replications of the TCL model were implemented though (especially during the 1980s when the rehabilitation paradigm was at its influential peak), the focus changed from a medically-oriented focus to a slightly more psychosocially-based focus.

Criticisms of ACT, on the other hand, clearly come from the empowerment-community integration paradigm. The concerns that are being expressed about the ACT model are entrenched in the values of empowerment, community integration and diversity. The empowerment-community integration approach has three key underlying values: (a) stakeholder participation and empowerment, (b) community support and integration, and (c) access to valued resources. Stakeholder participation and empowerment refers to the process by which individuals increase the amount of input and control that they have over their lives (Rappaport, 1987). Conversely, the biomedical approach attributes the label of expert to the service provider while the consumer is viewed as a patient or client (Nelson et al., 1996). This situation creates an imbalance in the power that is distributed between service-providers and consumer / survivors. The community integration - empowerment approach shifts this power imbalance into a sharing of power between service providers and consumer / survivors. This shift in thinking is facilitated by the belief that both consumer / survivors and service-providers have something valuable to contribute and learn (Nelson et al., 1996).

The value of community support and integration emphasises the notion of community belongingness. In order to become a *part* of community (as opposed to simply being *in* the community) individuals need to become integrated into normal community settings (Carling, 1995). The biomedical approach works mainly with individuals with mental illness in institutionalised environments. Even in instances where the approach may be used in the community (i.e., with ACT teams) the service is usually in vivo and often does not utilise outside community services to a very large extent. The shift in thinking that accompanies the emerging paradigm places an emphasis on the mutual growth potential that can come from enabling individuals with mental illness to fully integrate into society (Nelson et al., 1996).

The third key concept of the empowerment-community integration approach is access to valued resources. This concept, also known as distributive justice (Prilleltensky, 1994), encourages equal standards of housing, work, income, and education for marginalized people (Nelson, Wiltshire, Hall, Peirson & Walsh-Bowers, 1995). The biomedical approach often addresses such needs by providing specialised programs that lead to stigma and segregation from society (Nelson et al., 1998). The community integration - empowerment approach, on the other hand, places a priority on providing normalised opportunities and living independently in the community (Nelson, et al., 1998).

CHAPTER III

Conceptual Framework

Conceptual Framework

Qualitative Approaches to Research

Methodology refers to the philosophic framework and the fundamental assumptions upon which the study will be based (Van Manen, 1990). The methodology that guides this study is entrenched in the qualitative approach. In this chapter, I describe some of the significant differences between the empirical-scientific approach and the qualitative approach in order to justify my choice of the latter. Within the qualitative perspective there lies five traditions. I briefly explore these traditions and provide a rationale for the use of the phenomenological perspective in this study.

The empirical-scientific approach examines human behaviour which in turn is monitored, objectified, systematised and then rationalised into specific structured findings (Patton, 1990). The obvious argument that exists with regard to this approach is that it can only answer quantifiable questions such as "is there a decrease in the number of days spent in hospital for individuals who receive ACT services?" Although a strict adherence to what is measurable is important when one wishes to draw cause and effect conclusions from the data, it often comes at the expense of learning more about the subjective experience of the phenomenon. For example, studies examining ACT have primarily focused on the behaviour of those individuals who receive ACT services i.e., amount of time spent in hospital, the degree to which people use non-hospital services and the number of times people are compliant with their medication. This form of inquiry provides us with a knowledge of general trends across a number of people and allows us to measure improvement and declines in these trends. While this knowledge is extremely important in program planning and policy development, it is also important that the policies that we develop and the programs we implement take into consideration more than just general trends. Consider for a moment a student whose grades have fallen during a period of family turmoil. If one's only source of knowledge was based upon the lowered grades themselves one may conclude that the problem is that the student is not grasping the material. This conclusion, although not incorrect, is only half of the picture. Were one to delve further into the student's experience of the course, one would discover that the reason why the student is not grasping the material is because thoughts of her family problems are interfering with her ability to concentrate on the lectures. The added knowledge of *why* the girl is having difficulty will better enable her teacher to help her. It is important, therefore, that one consider multiple sources of knowledge when investigating a phenomenon.

The qualitative approach offers a way of researching subjective phenomena such as the lives of individuals, social movements and interrelationships (Strauss & Corbin, 1990). Strauss and Corbin (1990) describe the requisite skills involved in conducting qualitative research as the ability "to step back and critically analyse situations, to recognise and avoid bias, to obtain valid and reliable data, and to think abstractly" (p. 8).

The purpose of this study is to examine the subjective experience of ACT clients. The quantitative approach of monitoring and objectifying behaviour clearly would not be able to provide insight into such a subjective phenomenon as experience. Qualitative methods, on the other hand, enable the researcher to capture an individual's subjective experiences in a holistic manner through critical analysis.

Within qualitative methodology there are five main traditions: biography, case study, ethnography, grounded theory, and phenomenology (Creswell, 1998). I will briefly describe each tradition and provide a more extensive account of the tradition that I have chosen: the phenomenological approach. A biographical study focuses on the study of the individual and her or his experiences as described to the researcher. This type of study explores the entire life story of an individual and is written by a second party, namely the researcher (Creswell, 1998). As opposed to the holistic nature of the biographical study, the focus of a case study is on the study of a particular case or situation. The case may be a program, event, activity or individual but it must be bound or situated within a single setting. The data that are collected for a case study are a collective of multiple sources such as observations, interviews and relevant documents (Creswell, 1998). An ethnography differs from a biography or case study in that it provides a descriptive and interpretative account of a cultural or social group (Creswell, 1998). The ethnographic researcher observes the behaviour and customs of individuals who are bound together in a cultural group. Alternatively, the intent of a grounded theory, is to generate or discover a theory about a phenomenon and then paint a visual picture of this phenomenon (Creswell, 1998). The researcher is interested in how individuals act and react to the phenomenon. There is an attempt to relate emerging themes to form a conceptual scheme. Phenomenology, on the other hand, provides us with a way of capturing the inner feelings, thoughts and ideas of a personal experience. This approach is concerned with extracting from an individual what a particular phenomenon means to them in all its intricacies

The Phenomenological Perspective

The importance of phenomenology lies in the perspective of the approach. The phenomenological approach has at its core the personal experience of the individual. The purpose of the phenomenological method is to describe the experience in a way that captures the detail and full essence of the phenomenon without analysing, judging or explaining it. The researcher simply wants to understand a new experience and then allow a new understanding of this experience to become part of the knowledge base (Moustakas, 1994).

The challenge for this study will be to describe the experience of ACT and how the thoughts and feelings related to the experience of ACT affect the relationship to oneself and others. In the process of developing a description of clients' experiences of ACT, I hope to discover what ACT is and means to clients.

The insights gathered through a phenomenological study will not provide a personal history of an ACT client, nor a study of ACT clients in a particular situation, nor still an interpretative account of the ACT culture nor a substantive theory regarding the generalised experiences of ACT clients. The phenomenological approach will provide us with the meaning attached to an experience of a particular phenomenon, "to determine what an experience means for the persons who have had the experience and provide a comprehensive description of it. From the individual descriptions, general or universal meanings are derived, in other words, the essences of structures of the experience (Moustakas, in Creswell, 1998, p.13)." For the purposes of this study, the phenomenological approach is used to uncover the experiences, perceptions and interpretations of ACT clients.

There are four core tenets associated with the phenomenological approach (Creswell, 1998). The first, *a return to the traditional tasks of philosophy*, reflects a desire to return to a pure philosophy which is devoid of empirical science. The second tenet, *a philosophy without presuppositions*, reflects a suspension of all judgement regarding what is real until a greater foundation for judgement is provided. The third tenet, *intentionality of consciousness*, represents the assumption that the reality of a phenomenon is completely interrelated with one's conscious experience of it. *The refusal of the subject-object dichotomy* is the fourth tenet. This is the idea that the perception of a phenomenon is interrelated with the meaning that the experience holds for an individual.

Too often the knowledge that we posses regarding a phenomenon is based on external observations. Too often it is this type of knowledge that decisions and policies are based on. We need to incorporate first hand knowledge and knowledge based on experience into the repertoire of knowledge that underlies policy-making decisions.

Previous Qualitative Research with Consumer / Survivors

Although I am not aware of previous studies that have utilised the phenomenological approach to examine issues regarding ACT, other qualitative approaches have been used to examine issues regarding both psychiatric consumer / survivors generally and ACT specifically. In order to determine the perceived community needs of consumer/ survivors Lord, Schnarr and Hutchinson (1987) conducted a qualitative study in order to gain insight and understanding into the needs of psychiatric consumer / survivors and the significance that they attribute to these needs. According to Lord et al. (1987), the qualitative approach enabled the researchers to access the consumer voice which provided the study with a consumer perspective of needs. This personal perspective, in turn, enabled the researchers to "grasp dilemmas and contradictions faced by powerless people" (Lord et al., 1987, p. 34). The wealth of information that was derived from using the qualitative approach in this study allowed the researchers to determine that many consumer / survivors felt strong community needs in the areas of employment, housing, money and self-help groups. Issues regarding stigma, friends and support were overriding themes, which came up regarding all areas of community life. This rich interpretative data could only have been accessed through a qualitative methodology.

To my knowledge, only Estroff's (1981) work has examined ACT from the perspective of the client. Estroff's work allows us to vicariously experience the ACT culture through her observations. The current study is meant to add to the knowledge provided by Estroff's work by examining the *meaning* of the ACT experience for ACT clients.

Research Purpose and Questions

Moustakas (1994) states that "the first challenge of the researcher, in preparing to conduct a phenomenological investigation, is to arrive at a topic and question that have both social meaning and personal significance" (Moustakas, 1994, p. 104). The purpose of this study is to answer the question "how do clients experience Assertive Community Treatment?" In qualitative research several methods are available for exploring the research question: direct observation, focus groups and in-depth interviews. Typically in the phenomenological investigation the long interview is

> the method through which data is collected on the topic and question. The phenomenological interview involves an informal, interactive process and utilises open-ended comments and questions. Although the primary research may in advance develop a series of questions aimed at evoking a comprehensive account of the person's experience of the phenomenon, these are varied, altered, or not used at all when the co- researcher shares the full story of his or her experience of the bracketed question (Moustakas, 1994, p. 144).

I have chosen to use in-depth interviews as the method for this study in order to capture the experiences of ACT clients and to develop a richer and deeper understanding of the phenomenon. I believe that the choice of personal interviews reflects the guiding methodology of the phenomenological approach. The words of individuals receiving ACT services will provide meaningful descriptions of ACT that will enable phenomenological interpretations.

Development of Interview Questions

Formulation of advisory group.

The goal of the interview is to extract from the participants the meaning that they attribute to their experience with ACT. It is important, then, to ensure that the questions asked in the interview are such that they encourage participants to share their experiences with, memories of, and reflections on ACT. In order to be certain that the interview questions will allow participants to share the meaning of their experiences, the interview questions were developed from the results of a small focus group with two psychiatric consumer / survivors. One of the participants in the group is currently a client of an ACT program while the other individual has received community based services in the past but not specifically ACT. The focus group question that was asked of these individuals was "What is the best way to encourage psychiatric consumer / survivors to discuss the meaning that their experiences of ACT have for them?" The focus group comprised of two, one-hour sessions in which the advisory group members discussed this topic with me. The final questions used in the interview guide were developed collaboratively during these discussion periods.

The ideas and concepts that emerged from this focus group suggested that it would be important to explore areas related to: (a) the value that clients place on ACT, (b) what ACT means to clients in the context of their daily lives, (c) the client / case manager relationship, (d) relationships with peers, (e) personal goals in areas of life such as employment, education, family and personal relationships, (f) the desire for the assistance of ACT in the pursuit of these goals and the desire for community integration.

Interviews. I initially contacted the clients of the program by phone. I explained to them the purpose of my study and ensured them confidentiality should they choose to participate in the study. When the individual expressed an interest in participating in the study I arranged to meet with her or him to provide her or him with a letter of intent (see

Appendix B) and to answer any questions that she or he may have had. Individuals who decided to participate signed a copy of the consent form (see Appendix C) and began the interview.

All interviews were conducted in a private place chosen by the participant. This allowed the participant the opportunity to select an environment in which she/he felt at ease. Three of the interviews were conducted in the participant's home and two were conducted in my office at Queen's University. The interviews lasted between 45 minutes and 1.5 hours, depending upon the participant's openness to discussion. In order to select the participants for this study, I contacted each person on the CIP client list (see Participants and Sampling, p. 52) until five people agreed to participate in the study. Seven people declined to participate in the study. Two were female and five were male. I was unable to make contact with three individuals who either did not return my messages or were never home when I called. Each interview ended with an invitation for the participant to contact me if they thought of anything else they would like to include (none did). A transcription was made of each interview. Each participant was asked to review her / his transcript and was invited to recommend any additions and subtractions that she / he felt appropriate (no one recommended changes to any part of the transcripts). Each participant received an honourarium of $10.00 for their time, effort and contribution. The purpose of this honourarium was to ensure that in return for the valuable information that is provided by the participants, something tangible is given back to the consumer community. Funding for the honourarium was provided by the "Variations on Assertive Community Treatment; A Study of Approaches and Client

Outcomes of Four Teams in South Eastern Ontario" project. Participants will receive a final copy of the composite findings.

Interview guide. From the ideas and concepts expressed in the focus group, emerged seven areas of concentration (see Appendix D for the complete Interview Guide). The first area focuses on the value that clients place on ACT as well as the importance that they place on the activities that they do within the context of ACT. The focus group members thought that, in order to determine the value that is placed on ACT by the client, it was important to begin the interview by asking about the types of activities that the client engages in during the week. By having the client discuss all of the activities that they are involved in during the week (not just those associated with ACT), it was thought that I would be more likely to determine to what extent activities associated with ACT dominate the persons' daily life.

The second area of concentration attempts to determine how the client conceptualises ACT. For example, a client may not be aware that ACT refers to a multidisciplinary team that provides multiple services aimed at maintaining her / his life in the community. Instead, a client may associate ACT with just their case manager or a weekly group. In order to determine what the client associates ACT with, I asked her / him to tell me what they think ACT does.

Relationships were determined by the focus group participants to be an important area of inquiry. These participants thought that it would be important to try to determine to what extent the client's level of satisfaction with the program was dependent upon the nature of her / his relationship with her / his case manager. It was determined that the extent to which the clients' circle of friends was made up of other ACT clients would also be important.

As ACT has often been criticised for not providing enough of a focus on psychosocial areas the focus group participants thought that inquiring about personal goals would be a way of examining clients aspirations in areas of employment, education, family relations, housing, income, social relationships and independence. In addition to inquiring about clients' goals in each of these areas I also asked whether the client currently desired to receive help from the ACT program in pursuing these goals or if she / he would rather pursue them on her / his own.

The fifth area of concentration is community integration. I examined whether the client had a desire to experience greater integration with the larger community and spend time with individuals who are not aware of their psychiatric disability.

The sixth area is concerned with the amount of choice and control that the client perceives she/he has over her/his treatment and daily activities. In order to discuss issues of power and choice, the questions in this section focused on the extent to which weekly activities are influenced by ACT.

Finally, in order to determine the types of ACT services that bring satisfaction to the clients and those that are not satisfying, I ask the client to share with me both her / his best and worst experiences with the ACT program.

It should be noted that in the actual interview questions I have referred to the ACT program as the Community Integration Program (CIP), instead of using the term ACT. I have done this because the clients of CIP have never heard of CIP being referred to as an ACT program. The program is always referred to by its name, CIP, therefore the clients would most likely not recognise the term ACT as referring to this particular program. As the interviews progressed new questions arose.

Participants and Sampling

As this study examined in-depth information, gathering information from a small number of people provided the study with enough information-rich data for analysis (Patton, 1990). Creswell (1998) states that phenomenological studies typically collect data from interviews with between 5 to 10 individuals.

I interviewed 5 ACT clients from the Community Integration Program (CIP): an ACT program located in the downtown core of Kingston, Ontario. I chose to work with the CIP program both as a result of its location in Kingston and because it is the one Kingston team in which I have not had prior contact with the clients (due to previous employment positions). It is important when doing a phenomenological study to ensure that the participants have experienced the same phenomenon. Creswell (1998) states that "it is important [that] . . . all participants experience the phenomenon being studied" (Creswell, 1998, p. 118). Due to the variable degree of fidelity found amongst ACT teams, the five subjects for this study were all selected from a single ACT program in order to ensure a commonality across experiences.

With regard to sampling strategy for a phenomenological study, Moustakas (1994) states:

> There are no in-advance criteria for locating and selecting the research

> participants. General considerations include: age, race, religion, ethnic and cultural factors, gender, political and economic factors. Essential criteria include: the research participant has experienced the phenomenon, is intensely interested in understanding its nature and meanings, is willing to participate in a lengthy interview and (perhaps a follow-up interview), grants the investigator the right to tape record, possibly video tapes the interview and publish the data in a dissertation and other publications (p. 107).

By selecting the participants from only one program I ensured that each participant has been subjected to similar experiences. Although participants were selected from one team to control for experience, inevitably clients had different case managers. As this thesis is embedded within the "Variations in Assertive Community Treatment" study, the selection of participants was limited to those participants who were randomly selected for the larger study. Participants for the larger study were randomly selected from four ACT teams located in the Kingston and Brockville areas: the Psychosocial Rehabilitation Program (PSR), the Assertive Community Rehabilitation Program (ACRP), the Assertive Community Care Team (ACCT), and the Community Integration Program (CIP). In order to maintain confidentiality, clients were randomly selected through the use of their casebook identification numbers. Once selection was completed, program staff were provided with a list of the randomised case book numbers and asked to approach these clients and inquire as to whether they wished to participate in the study. If a client indicated that they did wish to participate in the study the staff member filled out a form with the name of the client. This form was then submitted to the research team. The participants for this thesis were selected from the previously randomly selected group from the CIP program. Creswell (1998) suggests that a phenomenological study include five to ten participants. As I could not predict how much material would be generated from the interviews, I decided to begin with the minimum number of participants. Upon completion of the analysis of the five interviews I thought that I had acquired enough material to adequately describe the meaning of the ACT experience for my participants. In order to select the participants I began with the first person on the randomly selected CIP list (n=28) and contacted each person until 5 people agreed to participate in my study.

Program Description

The participants in this study were recruited from the Community Integration Program (CIP). This ACT program is governed by Kingston Psychiatric Hospital (KPH). However, the program itself is operated from a separate community site. There are approximately 90 active clients registered with the program with a client to staff ratio of 16:1. The CIP program is comprised of a multidisciplinary team of professionals who represent various health care disciplines including psychology, nursing, and social work. A psychiatrist is available to the team 12 hours per week. The team primarily utilises the admissions services at the Kingston Psychiatric Hospital (KPH) for hospitalisations. CIP shares its community site with a variety of vocational programs including several consumer-supported businesses and a transitional employment program. The program co-ordinator is a psychologist who is employed full-time but works 0.6 full-time equivalent (FTE) hours with the team and about one half of this time involves direct client service. Many of the residents who have entered this program were previously served by a psychiatric hospital on a long-term, in-patient basis.

The CIP team functions as the "primary therapist." Caseloads are shared and the program holds daily team meetings for treatment planning and scheduling for all clients. Twenty-four hour, on-call access to the team is available. After regular office hours clients of the program can reach the team through the KPH hospital switchboard. The total average for all contacts exceeds 18 contacts per client, per month. The average number of community-based visits per client is estimated to be 12 per month. The ratio of community visits to office visits is estimated to be 60:40.

The goals of the program and the services provided are consistent with the ACT guidelines established by the Ontario Ministry of Health (1998) in that clients meet the mental health reform definitions for serious mental illness, functional impairment and are in need of continuous high-intensity services.

Researcher Role

The role of the researcher and the relationship of the researcher to the participants in this study is somewhat complex. In addition to studying community psychology at Wilfrid Laurier University, I am also employed full-time as a Research Co-ordinator at Queen's University in Kingston, Ontario. The project that I am co-ordinating is a three-year evaluation of four ACT teams in the Kingston (3 teams) and Brockville (1 team) areas entitled "Variations on Assertive Community Treatment: A Study of Approaches and Client Outcomes of Four Teams in South Eastern Ontario." This project is funded by the Ontario Ministry of Health through the Canadian Mental Health Evaluation Initiative (CMHEI) and has received ethical approval from the Queen's University Health Sciences & Affiliated Teaching Hospitals Research Ethics Board (see Appendix A). My thesis is embedded within this larger study and as a result is supported financially (honorarium for participants) through CMHEI funds and I am accessing ACT clients who have agreed to participate in the "Variations in Assertive Community Treatment: A Study of Approaches and Client Outcomes of Four Teams in South Eastern Ontario" study.

As the project co-ordinator I have been at arms length from the actual data collection for the "Variations in Assertive Community Treatment" project. Clients who have agreed to participate in this larger study would be familiar with my name and position but would not know me personally.

Additionally, as a result of past work experience in the Kingston area I am very familiar with clients from two of the ACT programs that are being studied through the larger study. In an effort to maintain objectivity I have chosen to work with the one Kingston team with which I do not have any previous experience and would, therefore, be less likely to have any previous relationship with clients.

An advisory group has been formed to advise and guide the research process for the "Variations in Assertive Community Treatment: A Study of Approaches and Outcomes of Four Teams in South Eastern Ontario." The advisory group is comprised of representatives of four stakeholder groups: ACT clients, family members, ACT staff, ACT directors and the research team. The advisory group consist of 14 members: 2

ACT clients, 2 family members, 2 ACT staff, 4 ACT directors and 4 researchers. This committee meets once every three months. The advisory group is also involved in the guidance of all peripheral research projects such as the one outlined in this paper. Consequently, results of this study will be presented to the advisory committee upon completion.

Data Analysis

I have chosen to use the methods of transcendental phenomenology as outlined by Moustakas (1994). This method of transcendental phenomenology has been described by Creswell as a "highly structured approach to phenomenological study" (p. 53). There are four aspects involved in the process of retracting knowledge from phenomenological data: epoch, phenomenological reduction, imaginative variation and synthesis.

Epoch is the process by which one brackets or puts aside all thoughts, feelings and ideas that one has about a particular phenomenon. The purpose of this exercise is to ensure that the previous knowledge that a researcher has about a phenomenon does not interfere or bias the interpretation of the experience.

Moustakas (1994) describes the process of bracketing as:

> An ability to gaze either inward or outword, is indeed something that requires patience, a will to enter and stay with whatever it is that interferes until it is removed and an inward clearing is achieved, an opening, an intention directed toward something with clarity and meaning. Every time

> a distorted thought or feeling enters, the abstention must once again be achieved until there is an open consciousness. I envision a rhythm of being receptive, of being struck with the newness and wonder of just what is before me and what is in me while also being influenced by habit, routine, expectation, and pressure to see things in a certain way until at last, with effort, will and concentration, I am able to perceive things with an open presence (p.89).

A second dimension of the phenomenological process is phenomenological reduction. The premise underlying phenomenological reduction is that in order to achieve ultimate truth it is important that the experience be reflected upon from multiple perspectives. Each time we look at an object or phenomenon we see it from a slightly different perspective and each perspective of the phenomenon brings new knowledge. Take for example, a life-like wax figurine. Upon first view one may assume that the wax figure is a person. The second time one glances back at the figurine one notices that the "person" has not moved. On a third glance, one notices that the texture of the "person" seems wax-like. Finally, one concludes that the "person: is actually a wax figurine.

Moustakas (1994) explores the concept of phenomenological reduction by stating that:

> Each looking opens new awareness that connects with one another, new perspectives that relate to each other, new folds of the manifold features

> that exist in every phenomenon that we explicate as we look again and again – keeping our eyes turned to the centre of the experience and studying what is just before our us, exactly as it appears (p. 92).

The process of phenomenological reduction is also concerned with describing the qualities of the experience which enables us to bring forth the nature and meaning of the experience (Moustakas, 1994). Moustakas (1994) states that:

> The task requires that I look and describe; look again and describe; look again and describe; always with reference to textural qualities – rough and smooth; small and large; quiet and noisy; colorful and bland; hot and cold; stationary and moving; high and low; squeezed in and expansive; fearful and courageous; angry and calm – descriptions that present varying intensities; ranges of shapes, sizes, and spatial qualities; time references; and colours all within an experiential context (Moustakas, 1994, p. 91).

It is important to note at this time that in the process of phenomenological reduction there is a return to the self. Although there is a great effort during the epoch process to bracket all pre-judgements and to distance the self from the phenomenon, in order to describe the phenomenon there must be a return to self, as I can only reach beyond my own perception if I first recognise and attend to my own experience of a phenomenon. Moustakas (1994) highlights the importance of this concept when he states that:

> Ultimately we may be seeking an intersubjective description of what appears as phenomenal. We grasp the other's experience with the same perceptual intention that we grasp a thing or event presented to us (Schutz, 1967, p. 106). This self-reference, the return to self, is an essential requirement (Moustakas, 1994, p. 94).

According to Moustakas (1994) the steps involved in phenomenological reduction include:

> bracketing in which the focus of the research is placed in brackets, everything else is set aside so that the entire research process is rooted solely on the topic in question; horizonalizing, every statement initially is treated as having equal value. Later, statements irrelevant to the topic and question as well as those that are repetitive or overlapping are deleted, leaving only the horizons (the textural meanings and invariant constituents of the phenomenon); clustering the horizons into themes; and organising the horizons and themes into a coherent textural description of the phenomenon (p. 97).

The next step in the phenomenological process is imaginative variation. Imaginative variation is the process that is used to arrive at a deeper understanding of the experience: a description of the underlying dynamics of the experience and the themes and qualities that comprise how feelings and thoughts are connected with the phenomenon (Moustakas, 1994). Moustakas (1994) states that:

> The aim [of imaginative variation] is to arrive at structural descriptions of an experience, the underlying and precipitating factors that account for what is being experienced: in other words the "how" that speaks to conditions that illuminate the "what" of experience. How did the experience of the phenomenon come to be what it is? (p. 98).

The steps involved in imaginative variation include:

> (1) systematically varying the possible structural meanings that underlie the textural meanings; (2) recognising the underlying themes or contexts that account for the emergence of the phenomenon; (3) considering the universal structures that precipitate feelings and thoughts with reference to the phenomenon, such as the structure of time, space, bodily concerns, materiality, causality, relation to self, or relation to others; (4) searching for exemplifications that vividly illustrate the invariant structural themes and facilitate the development of a structural description of the phenomenon (Moustakas, 1994, p. 99).

Synthesis of meaning is the final step of the phenomenological research process. The process of synthesis is described by Moustakas (1994) as an "intuitive integration of the fundamental textural and structural descriptions into a unified statement of the essences of the experience of the phenomenon as a whole" (p. 100). This unified statement provides a synthesis of the meanings and essences of the experience for the entire group of experiences that are being studied (Moustakas, 1994).

Epoch

Epoch is the process of clearing one's mind of any and all biases toward a phenomenon. In order to truly hear the experience of another one must remove her/his own interpretation of a phenomenon from the picture. In order to do this the researcher first explores and states clearly her / his own thoughts and feelings of the phenomenon. The stating of the researcher's biases is viewed almost as a purging and it is assumed that the researcher is now able to temporarily suspend (bracket) her / his view of the phenomenon in order to clearly understand the experience of the phenomenon for another person without the obstruction of her / his own biases.

My purpose in pursuing this study is grounded in my own need to explore ACT and to come to some greater understanding of the needs of psychiatric consumer / survivors in the context of ACT. In order to explore this study it is important to recognise that the basis of my own final understanding of the experiences will ultimately be grounded in my own experiences, thoughts and ideas. I can only reach beyond my own perception if I first recognise and attend to my own experience of a phenomenon. In order to reach beyond myself to gain knowledge from another's experience, I must be willing to temporarily set aside my own feelings, thoughts and ideas about the phenomenon so that my own experiences do not interfere with my being able to truly hear another's story.

This process of "packing away" my own thoughts on ACT that have come from my own personal experiences, is not easily done. I am not sure that one ever truly becomes completely removed from all that one knows and strives for. Once I have opened myself to a point where I can truly *hear* what people are telling me of their experience of ACT, I am charged with trying to present or describe this experience using the voices, qualities, expressions and feelings of the storyteller. To do this I need to immerse myself in the words of the story-teller and to reflect back upon my own thoughts and feelings. I need to return to my own purpose of pursuing this study and keep open my mind to the possibilities of new or alternate perceptions, in order to find meaning and essences and deeper truth.

In setting aside my own assumptions and expectations, I must acknowledge and lay bare my experience both as a service provider and as a student of community psychology. In contemplating my own assumptions of ACT I realise that I consider ACT to be structured in a way that most likely directly disempowers individuals through lack of choice and community integration. Concurrently, however, I also believe that the field would not be where it is today conceptually were it not for the perception that individuals with psychiatric disorders could maintain lives in the community; a perception which was first initiated by models such as ACT. No paradigm or philosophy exists solely unto itself. Each is comprised of a series of ideas, thoughts and conceptualisations that come together to form a larger theory or perspective. The ideas and thoughts that comprise a paradigm build continually until the paradigm is strengthened and then ultimately discarded when it no longer addresses this ever-expanding body of knowledge. Each concept, each perspective, each paradigm has somehow been affected and influenced by the one that came before it. In keeping with this, it is my perception that ACT was the first step in a long road toward citizenship for individuals with psychiatric disorder.

CHAPTER V

Presentation of Data

Presentation of Individual Data

In this section I present the data for each individual participant. The experiences of each participant are presented in the form of an individual textural description and an individual structural description. The individual textural description provides a description of the way in which each individual experiences the phenomenon. Each description is constructed from the themes and horizons (the statements highlighted by the researcher as relevant to the topic and research question) that arise from the text. The individual structural description, on the other hand, provides the researcher's interpretation of the structures that underlie an individual's experience: in other words *how* the individual experiences *what* she / he experiences.

Individual Textural Description: Sharon

Sharon is a 48 year old mother of two girls. Sharon and her former husband spent the majority of their married life teaching in Zaire, Gabon and Mali Africa, and raising their two children. The family moved back to Canada off and on during their teaching periods in Africa and finally settled in Canada for good in 1996. Sharon became ill shortly after their return. Sharon and her husband were divorced soon after the onset of Sharon's illness. She moved to Kingston with her two daughters and entered the welfare system. Sharon was eventually admitted to the Kingston Psychiatric hospital where she was diagnosed with Schizophrenia. While Sharon was in the psychiatric hospital she was evicted from her co-op apartment and her children were put in foster care. Sharon became involved with the CIP program immediately after leaving hospital and has been with the program for two years. Her children now live with their father in Quebec and Sharon has just recently married another member of the CIP program. Both Sharon and her current husband live in their own apartment in Kingston. Sharon supplements her disability income by selling Avon. She also volunteers as a tour guide at Kingston City Hall. The interview with Sharon was conducted in my office at Queen's University. The interview lasted an hour and a half. Sharon was very willing to do the interview and was very talkative. Sharon was very good at articulating her thoughts and feelings around ACT. I found that in many cases just asking the open-ended question did not elicit as much information as I would have liked. However, after one or two prompts Sharon had answered most of my questions in each category.

Sharon experiences Assertive Community Treatment primarily within the context of her relationship with her psychiatrist and case manager. For Sharon ACT *is* her relationship with these two primary people. The purpose of *her relationship with her case manager is very similar to that of a companion or ally*; "someone to vent things with or to turn to, consult with or ask for advice, sort of a support thing." Whereas, *interactions with the psychiatrist deal primarily with medication*, for Sharon ACT is also a resource with an address, easily accessible telephone and fax machine and a receptionist who is "always in the office."

For Sharon, a primary experience of ACT is that *too much emphasis is placed on medication*. She feels inundated by questions and concerns related to medication. This focus on medication becomes all consuming to the point where she feels that other important life issues become secondary.

> I feel that [ACT staff] are just figure heads, and they always come back to their list, like if you get talking about stuff and their like, the medicine, how is the medicine? You know and don't take a stand pretty much on anything ...like they keep referring to the medicine three or four times during the space of a 20-30 minute talk.

Sharon resents what she sees as a narrow focus on one aspect of her needs. She feels a loss of control over where emphasis will be placed in her treatment, "...for them, everything resorts to a pill."

Community integration is of primary importance to Sharon. It is this area where she feels that primary focus should be placed. True integration occurs when a person becomes active in all areas of their life; friends, jobs, social activities. For Sharon, working and getting paid for meaningful employment is the largest and most important step in becoming re-integrated into society. There is a feeling that you are worthwhile and valued by society when you get paid for what you contribute.

> I will feel 100% integrated when I get a regular pay cheque. That is an integration, it is considered that your work merits a salary, and that is a big thing to feel, that you, someone feels your work merits a salary. That gives you a sort of a feeling of satisfaction.

In order to achieve true integration one needs to gain "self-esteem", "confidence" and "self-assertion" skills that can be transferred into successful interactions with people in the community. Sharon believes that these skills are the keys to true integration and that more emphasis must be placed on their development through workshops and social activities. Sharon expresses disappointment for what she sees as a *lack of priority placed on the development of skills that underlie a person's ability to fully integrate into society.*

> I think [ACT staff] are supposed to help people re-integrate into society right? Well, I don't think they do that at all, very much, so, and they don't say how can I help you find out where you can get more self-esteem, how can I help you find out where you can have more confidence so that when you do look to work, you will come across as confident enough to be considered a candidate, and stuff like that. How can I teach you how to be more assertive in relationships and not come across as aggressive when you get frustrated, so that people don't get scared of you and you don't get readmitted to hospital…

Often, the experience of ACT leaves Sharon feeling like there is *no connection to family.* The strains that family members are put through when mental illness strikes a loved one can separate a family:

It is almost as if [families] are scared to find out more or to get involved, or to get

> closer to the issue or to figure out, you know stuff about it, to try and understand, it is like they really believe that mental illness is a virus and you might catch the virus if you get too interested.

There is a desperate desire to gain a helping hand in putting these relations back together, and a feeling that more could be done by ACT in this regard:

> I think [ACT] could do more with regard to calling people's families and saying, you know, we would like you to come and see us because, you know maybe the family has an environment, or the family attitudes could have been part of the problem, or could make the situation a lot better from now on ...

A resentment and an anger exists in situations where *ACT staff do not provide direct assistance in areas related to finding work, family issues and social activity.* Sharon interprets the lack of direct assistance in these areas as an unwillingness on the part of staff to engage in matters that fall outside the realm of medication. Sharon believes that in many situations the support is not intense enough to fill particular needs because staff do not care to get too involved in the lives of their clients. There is a feeling that they should be more active in a direct way; *do* more.

> I tell them about things with my kids, and concerns and stuff like that and they, well, they are not that involved, or they sort of just...say, well, give it time, ... like I don't get that much satisfaction talking to them

> about each thing, it is like they just want to have minimum involvement... It seems that they feel threatened when you...try to say, well, is there anything you people can do? I am really concerned about my children, I don't have input, could you call their father, talk to them, and I want somebody, I am really concerned about those kids, I think they are really mixed up, you know...oh well, how's your medicine going?...You sort of say, okay well, you guys are, you don't want to take a stand that much do you...?

At the same time, the need to be independent is just as strong as the need to have someone to depend on. There is an *acknowledgement of the fact that recovery can only come from within.* Consequently, there is a strong desire for space and autonomy in the pursuit of personal goals:

> I can tell them my projects and then get their advice and talk about certain aspects of it or, you know, if they have to, if I have to borrow money, they would tell me you could only do part of it. or something like that, but I mean , if I am going to follow it through it is because I am really interested in it.

Sharon believes that situations occur in which independence is not stressed enough as a result of *staff not being willing to "let go" of clients.*

> Some of those so-called workers themselves, they are a little bit put off, they see people moving out of these group situations who don't need them

> anymore, who have gone beyond that ... Well, I don't feel that they are ready for people to evolve. You know for them that's pretty threatening and that's all I can say...

For Sharon, the relationship between herself and her social worker is extremely important. In many ways the psychiatrist and the social worker are the only people from ACT that Sharon has contact with on a regular basis with the case manager being the primary contact. In Sharon's eyes the case manager is "...the mirror, you know what is offered through them...because they are the first person you contact..." *The purpose of the relationship with the case manager is to provide support*: personal support, support around resources, a person who will guide when guidance is needed and who will give a helping hand when that is needed. *It is important that there be a feeling of genuine interest on the part of the case manager.* Sharon wants to feel that her case manager is interested in who she is as a person. She wants to work with someone who has both the time and interest to become involved in her life, much like a companion.

> If [case managers] are really outgoing and giving you information about stuff you could be doing, or stuff that is offered and what is going on, or how you can get involved in stuff, well, then it is great, all that much better. But if they give you the impression they have 5000 people as a case load and you just phone they have three minutes to talk and the phone is ringing, so it is kind of superficial, I just think well... they don't have much time to

> get that involved in my life, or give me much help…

A major concern for Sharon is the feeling that there is *little opportunity for growth within the relationship with her case manager* or to address changes in the service from what it was when she first entered the program. She feels that there is little opportunity for clients to be viewed in a continuously changing, dynamic state.

> It seems, once they got somebody categorised, this is the file, well put that file there, it stays there, and that file sits well there, it is nice and orderly we are not going to look at it, open it and read it over and say, that person doesn't seem like this now….

In Sharon's experience the treatment and expectations on clients are based solely upon the assessment (physical, social, emotional) they first receive upon entering the program.

A further concern for Sharon is the *professionalisation of ACT staff*. Titles and positions enable the case manager and psychiatrist to keep their own individuality out of the relationship with the client which in turn serves to de-intensify the relationship. For Sharon, this *professionalisation facilitates an unequal and distant relationship*, "I think they are hung up with their titles of professional, so that they are afraid to come out from behind it." This feeling of unequal footing is obvious when compared with the relationship to support staff with whom Sharon feels more comfortable, "I have V, who works there, she works there all of the time and I send faxes through her, so I can get my divorce procedures completed, the employees there I consider as my equal, more than the professional people."

Sharon believes that *there is room for choice around goals*; to decide to pursue what is within your means or to decide to put certain goals on hold or not to pursue a particular avenue. "We don't always have the means to do everything we would like to do, but you have choice to work towards it or say, oh that goal is really too far." There is no control, however, over how case managers and psychiatrists react to the choices of clients. There is frustration regarding the lack of control over how the case managers view clients. "I don't have any choice over their attitudes…you know I can't make them change their attitudes or make them re-examine their initial diagnosis, or say, maybe we should re-evaluate this person, you know I can't do anything about that."

For Sharon *it is ideal to have solid relationships in both the consumer and non-consumer communities*. There are extremely important benefits that are offered by both communities and to neglect one or the other would mean missing out on some of those benefits. The consumer / survivor community offers comfort, support, empathy and acceptance, "you can be with the people who have been through it like you, so you sort of feel like more family with them and you know that they are not going to be down on you if you blow your cool." The non-consumer community, on the other hand offers a chance to live in the "real world" which is an extremely important part of recovery and community integration. By associating with people from the non-consumer community you "learn how to cope in the real world." It is essential that you deal with the real world, "you have got to know about it."

Sharon believes that the *most important element of care is believing in people, their abilities and potentials*, even if you have to give them a helping hand to get there.

Sharon describes her frustration at an event that was organised by the ACT team for a summer get together in which she felt that this belief was lacking. Staff took clients of the program to the beach "…everybody was just sitting around waiting for the meal, and they didn't organise any games or sports… you felt like you were just, they thought you were such a vegetable that you couldn't even do a relay race…it was a sort of half-hearted affair, you know, like they didn't get into the spirit of making it exciting."

Overall, Sharon feels that the changes that will happen in her life around her goals for a job, house, greater community integration and greater family contact will occur as a result of her own efforts as opposed to those of a case manager or other ACT staff. Of this she feels both pride and resentment.

Individual Structural Description: Sharon

The structures that underlie Sharon's experience of ACT are expressed in her experiences of ACT as a one on one dynamic with one or two other people who are there to help her meet her needs. Sharon *does not conceptualise ACT as an agency or team that provides multidisciplinary services* because all of her encounters occur at an individual level. To a smaller degree, Sharon does recognise *ACT as a resource* that lies outside of the relationship with her psychiatrist and case manager. It is an opportunity to utilise tangible resources that may not be otherwise affordable. She sees these resources as opportunities to connect her to the outside world.

Sharon feels *frustrated with her relationship with her case manager*. There is a desire for a more intimate involvement. She describes her frustration with this relationship in a way that suggests that *what she wants is a friendship.* Sharon also senses, however, that the *professionalisation* of the relationship between herself and her case manager *creates a barrier* that keeps the relationship from truly gelling. Additionally, Sharon experiences an underlying resentment around the time that is taken away from this relationship to be devoted to other clients. The general disappointment toward the client – case manager relationship seems to stem from *the inconsistency that exists between what Sharon hopes to get out of this relationship and the type of relationship that can only emerge out of a professionally oriented service.* Unfortunately, the very nature of ACT doesn't allow the case manager to be a true companion. ACT, as it is currently structured, is a professionally oriented service that provides intensive case management to ten clients per one case manager. Within this context Sharon will always feel that she is one of many and that *the case manager or psychiatrist are too busy to become fully involved in her life.* The lack of clarity around the nature of the relationship with her case manager results in Sharon's experience of resentment and frustration. She feels that she is being let down and this resentment hinders the other aspects of the relationship.

For Sharon, the type of support that she receives from ACT can be broken down into two facets: *the focus of support and the level of support.* In Sharon's experience the *focus of support is unbalanced.* The seeming primary importance placed on issues around medication is difficult for Sharon. She wishes to de-emphasise treatment. In Sharon's perception the *constant emphasis on medication* does not address the desire to work and integrate with the community. *It places an emphasis on illness as opposed to* *recovery*. As Sharon walks along the path to recovery there is always this constant juxtaposing entity that tears her focus away from recovery and forces her to focus on illness. It is frustrating for Sharon to not be a part of society in the way that she was prior to becoming ill. There is almost a desperation for something to happen to return the fullness of being that she once experienced. She wants everyone around her to *focus on her recovery*: to *focus on life areas such as community integration and work*. She questions whether others could do more in this regard: could psychiatrists de-emphasise the priority they place on medication? Could case managers become more involved in life areas and less focused on symptom assessment? Could more services be provided that are designed to integrate?

Sharon's preferences around level of support present an interesting push and pull between wanting service providers to actively participate in direct activities that will facilitate her recovery, and recognising that the route to true recovery lies in her own actions. Sharon experiences resentment when the level of the support is too far either side of the spectrum. This resentment is directed toward service providers but does have some reflection on Sharon's own ambivalence around her recovery. In areas where she feels strong, she has an equally strong desire to be independent. Where she is unsure, however, there is still a desire that exists to take on the role of the client and have things "done" by others. Often, Sharon finds herself in a position of wanting ACT to provide direct assistance in areas where direct assistance may be counter productive to achieving her end goal: independence. This is most likely due to previous experiences that Sharon has had, both with ACT and with other areas of the mental health system, where services have been provided for her rather than guiding her to accomplish things on her own. As a result Sharon has difficulty conceptualising any other way in which assistance could be provided.

At this point in her recovery, community integration is clearly where Sharon's concerns and efforts centre. For Sharon, *the underlying foundation for successful community integration lies with self-esteem, self-confidence, and self-assertion.* These are areas that Sharon lacks confidence: areas where she feels that she needs to do more work. In Sharon's experience ACT does not approach community integration by providing opportunities to build this foundation. Sharon's concern over her own ability to interact effectively in the community is heightened to the point where she associates ineffective or inappropriate interactions with re-hospitalisation. Clearly Sharon feels at a loss as to how to communicate and socialise in society. Sharon feels that she was given the opportunity of experiencing community interaction without first having a foundation of esteem and confidence. This experience has resulted in confusion and fear of interactions in the community. This is an area where Sharon is looking for involvement from her case manager, someone to show her how to start on the road to building this foundation.

A strong connection exists between this diminished level of comfort around community interactions and the tendency to view the consumer/survivor community as safe, tolerant and understanding. The way that Sharon describes her feelings for the consumer/survivor community suggests that she experiences considerably less pressure (whether real or perceived) to communicate or interact in any prescribed way.

Interestingly, Sharon associates the non-consumer community with the real world, a competitive world that cannot be escaped. This view seems to suggest that the consumer / survivor community, although safer, is also somehow less important for Sharon than the larger community.

In summary, Sharon's experience of ACT is one of ambivalence. She feels that she has achieved many things that have improved the quality of her life. However, she attributes many of these successes to herself alone.

Individual Textural Description: Margaret

Margaret was born in Toronto 47 years ago. Margaret found school very difficult. She saw her first psychiatrist when she was in grade 8. Margaret has been in and out of hospitals since she was diagnosed with uni-polar depression at the age of 15. Margaret married another consumer / survivor when she was 17, and they have now been married for 25 years and own their own home on the north end of Kingston. Margaret has had a sporadic work history. She and her husband enrolled in George Brown College when they were first married in a chef-training course but Margaret became ill halfway through the course. Since then Margaret has worked in a few restaurants as a bus girl and as a dishwasher. Currently, Margaret is unemployed and has not worked for several years. Margaret became involved with the CIP program seven and a half years ago. The interview with Margaret was conducted in her home and lasted one hour. Margaret was very willing to participate in the interview. At first, she was a little uneasy about the amount of time that it would take to complete the interview. However, once we started the interview she was fine. Margaret required a lot of prompting as she didn't respond a lot to the open ended questions.

For Margaret *the experience of ACT is one in which she feels as though she belongs.* There is a feeling of knowing that she is cared about and that she has a place to go to for help. "I feel like I belong to something, like that I am a part of the community that will help me." She feels secure in the knowledge that the help that she will be given will be in her best interest:

> The best thing, I didn't know at the time, but the best thing I needed was to go to the hospital and they planned it out and I did go to the hospital and everything worked out you know, so that was good.

For Margaret *the main purpose of ACT is to help her with her illness*, "I think they are there to help you…when it is hard to cope with your illness to sort of talk you through it." ACT is a "one on one" relationship with her case manager who comes to see her once a month and a psychiatrist who she sees every few months. Margaret does not view this relationship as an all encompassing element in her life. "Basically, that is what it is, the nurse, the doctor I see, so there is not really, I don't do too much with them, you know…really, [ACT] is kind of independent of my life you know." Margaret describes *her interactions with her case manager as involving conversations around her illness* "how I am coping with my illness and how I feel physically and that, mentally and that…if I am feeling really down, you know, I would like to have somebody to talk to about that…" The most important aspect of her relationship with her case manager and psychiatrist is knowing that she can rely on them at any time, "that is the most important thing, you know, if I really need them…there is somebody to call."

Margaret often finds that she is bored. *She feels frustrated and sad over the lack of activity in her life*. There is a sense that if she did more she would get a greater sense of satisfaction out of her life. Margaret describes her week as involving "housework, reading, watching television and listening to the radio, not too much, I would like to have more things to do but I kind of stay at home bored, I am really bored you know."

Although she is living in the community, in a home with a husband and a few friends, in many ways *Margaret feels abandoned by life*. She senses that there could be more purpose for her:

> Life is kind of too easy for me right now, it is not hard at all. I don't have any major decisions or anything, I don't have very many choices, I don't make too many you know…I find one day goes into the other, which makes me kind of upset you know.

Margaret can see what some of these other things might be; a job, education, social activities. *She has a strong desire to fill her life with these things; to put more activity into her life*. Margaret describes her overall objective as a desire "to do more than I do now. To meet more people and that." Her personal goals within that objective are to:

> Have a job, meet more people…[get] out more, more hobbies and having a closer relationship with my family than I do now…I would like to see a

> bowling group or something, I could go once a week, at least once a week, go bowling you now, or have more picnics and stuff you know. Or I like the apple picking and that, it was good...playing, doing things, sport, going for walks, stuff like that I guess.

Margaret is experiencing a struggle in conceptualising the goals she wishes to pursue and how she will pursue them. Margaret believes that it is her responsibility to pursue her goals. She feels that the onus is on her to initiate and maintain her pursuit of these goals. "I think it is up to me...I guess it is basically up to me." A job is seen as the open door to the outside world, a way to access a life. She feels that by accomplishing her goals she will become more integrated with society:

> Right now, I don't really feel that way, integrated into the community. I just feel that I am part of it but on the outside...I don't know, maybe, if I met more people and if I had a job and stuff...if I knew more people in the neighbourhood you know.

In the end, however, Margaret has some very large reservations about pursuing her goals:

> I am bored, but yet I am also afraid that if my life got too complicated would I be able to handle it, you know. That's what I am afraid of you know. I sort of, you know, got too easy a life, but I don't want you know, life to be too hard, but I find life is way too easy right now.

Margaret doesn't really talk about her goals with her case manager and psychiatrist, "we don't really do that." She has primarily developed an interest in these particular goals as a result of her own past experiences and personal desires. Although Margaret wishes to pursue her goals and sees them as her responsibility, she seems to be stuck in non-action by a lack of confidence in her ability to obtain success. When she discusses her goals she does so in a way that emphasises an underlying lack of self-confidence:

> Maybe in five years, I might not have a job yet, I might have a volunteer job, but not a paying job, you know…it is just, I don't really see myself working now and I, you know, it is hard getting a job in the first place.

As a result, Margaret has not begun to pursue or to initiate pursuit of her goals. Possibly this is why she also desires that ACT become more involved in providing opportunities for her. *She believes that ACT could help her to pursue her goals by providing structured services aimed at providing opportunities to engage in socialisation.*

> Maybe, if they could have a group, a talking group sometime you know, to just talk…a social group…meet people…They should also have a program you know, where you socialise more and that, sort of like a discussion group you know. Where you do things you get out into the community and you do activities you know. Like sometimes, they go apple picking and that, I would like to see more things like that.

For Margaret it is important that her case manager cares about the job that she is doing, that "she is doing it because she is concerned about me…I think she has to care you know, and she has to be the sort of person to be able to talk, bring you out you know." Margaret's relationship with her case manager is extremely important to her.. Margaret describes *She feels very close to the woman who is her case manager and experiences a bonding with her that is akin to that of a confidant* her relationship with her case manager as that of "a friend, a girl friend or something." In many ways this relationship resembles a closer confidant than a regular friendship. "In some ways, I can open up more with [my case manager] than I can with [my friends]."

Margaret has a strong desire to fill her life with more people and in particular people who do not come from the consumer/survivor community. "I would like to see other you know, people, outside that [consumer/survivor] area more." *She feels strongly that only associating herself with the consumer/survivor community is unhealthy, that it creates an unbalanced emphasis on illness.* "You know, I don't really want to be concerned with psychiatric survivors all the time you know, because people who have these problems tend to talk about their problems a lot more you know." Margaret believes that the non-consumer community would offer her more in terms of a healthy outlook on life. She feels that the nice aspect of joining the non-consumer community would be that they would talk about "anything besides their problems."

Choice is something that Margaret doesn't feel she has a lot of. She wants more. Choice is an issue that comes up in so many aspects of Margaret's life and affects her on various levels. On the level that affects her immediate surroundings, she feels she does have choice within the constraints that are placed upon her:

> Yah, I have a choice to make the best of my own life, they show you that you

> have a choice to make the most of life or not…you know, it is up to you, I guess, everything is up to you basically when it comes down to things like, the ultimate choice is yours, what you want to do.

At the level that involves the ACT program, Margaret is ambivalent with regard to the amount of choice she has. In some ways she feels that she has an important influence and choice around her medication. She feels that she has input with her psychiatrist into what medication she is on. She values this input and is proud of the results that it has facilitated. "I feel that I made the right choices on medication. I am on Lithium so I feel that I am on the right medicine, so I made the right choice." In other ways Margaret believes that she has very little choice over other aspects of ACT. She describes a situation in which she did not have a choice over who her psychiatrist would be. As the psychiatrist plays an integral role in her relationship with ACT, Margaret was very disappointed in her lack of choice in this matter.

> When I had really no choice, I just sort of had to see this doctor and that was it…I wanted a choice, but they don't really have a choice, they don't really have many psychiatrists, you know. So, I think they should have more psychiatrists, there you know, so they give more people choices.

Margaret experiences a significant amount of frustration around her lack of choice at a systems level. She feels that her life is severely impacted by systemic issues over which she has no control.

> I don't have really good education and I don't really have a choice of too much jobs…it makes it impossible to have a choice if you know the amount of money I make and that.

Overall, Margaret's immediate experience with ACT is positive. She feels confident about the role that ACT has played in relation to her illness. However, she is very disillusioned with what her life holds for her.

Individual Structural Description: Margaret

The structures underlying Margaret's experience of ACT is best expressed within the context of her daily activities. Margaret experiences her daily life as lacking in activity. Margaret's whole life revolves around her home and what is contained within it; housework, the television, her husband and the visits that she receives from her case manager. Margaret describes herself as bored; she feels that she should be doing more outside of the home and should be more active. At the same time that she feels this desire for more activity, however, she also experiences a deep seated fear that she might not be able to handle more in her life. Margaret worries about the impact that too much activity would have on the state of her illness. This personal conflict has resulted in an inability to initiate the pursuit of her goals on her own accord. Although she recognises that the responsibility to resolve this conflict lies with her, she has placed this responsibility on ACT.

Although Margaret does not require many services from ACT, *she depends on her case manager for company*. Her case manager is someone who will come and visit regularly and fill some time in Margaret's life. As Margaret's life involves so few elements external to her home, this is extremely important to her. This relationship is also important to Margaret because her case manager is one of the only people in her life who is not a consumer/survivor. As a result, this relationship is one of the very few that lets Margaret experience a relationship with a non-consumer/survivor which, in turn, represents to her a safe step in pursuing her goal for community integration and acceptance by the non-consumer community.

Margaret feels that all of her basic needs have been met at this point in her life: living in the community, secure housing, an effective medication regimen and a support system that she can turn to if anything goes wrong. Margaret attributes ACT with meeting her basic needs and feels very grateful to them for providing this. *Margaret's goals, however, involve needs that are higher order.* The type of needs that come about once basic needs have been met, the need for a job, friends, education, activity. *For Margaret, these goals represent the difference between survival and having a life.* These life goals are not being met in her life currently.

In one breath she will tell you that she feels it is her responsibility to pursue these goals on her own. However, in the next breath she will tell you that she can't actually see herself beginning to pursue these goals without the help of a very structured, pre-arranged plan implemented by someone else. She lacks confidence and is unsure of her ability to pursue these goals. Unfortunately, in the end Margaret probably will not attempt to pursue these goals unless it is done for her. This is why Margaret has a desire for ACT to play an integral part in organising the activity in her life. She sees this as a solution to her struggle. Ironically, however, if Margaret possessed the self-esteem and confidence that she is seeking, she most likely would be able to pursue these goals on her own.

It is as if after meeting basic needs there is another step that must be provided before she is able to pursue her recovery independently. There is a need for services devoted specifically to building the self-esteem and self-confidence that is necessary to be able to become independent in the pursuit of one's goals.

Margaret is discouraged by the lack of choices in her life. Margaret finds that a lot of choice has been taken away from her as a result of the larger system. She feels that her choice in jobs is limited due to her level of education. *The amount of money that she receives takes away a lot of choice.* Within ACT she feels she has some choice. She feels that she has influence and choice over small things in her life such as what she will do with her day. However, she experiences disappointment over her lack of influence and choice in a psychiatrist. The lack of choice in Margaret's life impacts on the amount of responsibility she has in her daily life and the way she feels about herself. Margaret feels a lack of worth: like she is somehow very unimportant in society. These feelings of worthlessness feed into her sense of low self-esteem. Margaret is resentful of the system that has stripped away her ability to implement choices concerning her own life. However, she feels helpless to do anything about it.

Overall, Margaret's life is for the most part very empty. She is grateful to ACT for addressing many of her basic needs quite adequately but *she experiences a hollowness that stems from so many still unfulfilled needs.*

Individual Textural Description: John

John is a 47 year old, single male. John grew up in Gananoque, just outside of Kingston, where he attended high school until grade 10. After leaving high school, John became a bit of a drifter. When he first left home, John moved to Toronto for a year where he worked as a shipper / receiver. After a year, John moved back to Gananoque to live at home and do odd jobs. When John turned 21 he hitchhiked to Vancouver where he stayed for 3 years "just hanging out" in night clubs and working as a dish washer. From there, John "kicked around South-eastern Ontario" until he settled into a five- month food preparation course at George Brown College. John has continued to travel around obtaining positions as a cook's helper in various places throughout South-eastern Ontario. Currently John supplements his disability pension working as a chef's helper at Kingston Penitentiary. John has been located in Kingston and receiving service from the CIP program for the past seven and a half years and lives in his own apartment in downtown Kingston. Diagnosed with both schizophrenia and a substance abuse disorder, John has a history of being in and out of hospital numerous times over the past twelve years. John did not show up at the scheduled time for our interview. I called John (once he was 20 minutes late) to find out if he was still coming. John called me back five minutes later to say that he had fallen asleep and forgotten about the interview but that he could come over right away. John and I conducted the interview at my office at Queen's University. John was able to articulate his thoughts and feelings quite well. He kept insisting that he really wouldn't know any of the services offered by CIP as he tried to "stay away from psychiatry."

John conceptualises ACT as a single relationship that exists between himself and his case manager. As John sees it, *his case manager is involved in his life to aid him with obtaining his basic needs*. John periodically sees a psychiatrist who is associated with ACT; his case manager also attends these meetings. For the most part, all of the needs that are fulfilled by ACT for John are addressed by the case manager. Consequently, *John feels very close to the woman who is his case manager and has come to rely on her*. John depends on ACT for support and assistance in areas that relate to basic survival needs such as access to medication and help with issues around personal care, both physically and mentally:

> [ACT] just means that I got some help with problems that you run into being on your own after being in hospital…[my case manager] makes certain that I get my medication renewed, live half decently…[there is] somebody that will give you a helping hand to get things organised in your life.

John sees ACT as a small part of his life and feels that in many ways he has been instrumental in ensuring that ACT remains on the periphery of his life. The only assistance that John wishes to procure from ACT is with regard to his basic needs. John feels very strongly that ACT not become too involved in his life, "I try to stay away from psychiatry as much as I can, just take my medication and try to live half decently."

John feels the need for support from ACT but is cautious of having that support become too intensive in his life. He is very resistant to receiving any support that goes beyond his basic needs. *John feels that he must put limits on the support that he* *receives or it could encompass his life to a point where he would lose his independence.* Still, he does feel that he requires the support of ACT to meet his most basic needs: for example, making sure that he has full access to his medication, someone to "keep him on track" so that he can take care of himself and his home properly:

> [I] just [want to] have someone there to keep me on track... with a decent living...just by making certain I did things, like get my medications so I can go to work. I don't like the limitations of having someone looking after my affairs...I look after everything.

John experiences a trusting and respectful relationship with his case manager. He relies on his case manager for many services such as ensuring that he has proper access to medication, providing him with transportation:

> [she helps me with] my medication, she is going to keep it coming to the clinic down there and if I can't get down, bring it up to me...[I like] getting rides home from my appointments with M, [when] she just happen[s] to be on her way out the door.

John relates to his case manager as a friend. He feels that he can open up to her and share with her as he would a companion. "[She] is friendly and easy to get along with and she is easy to talk to and to explain things to...[I see her] more like a friend."

John's life is filled primarily with work. He is employed in a full-time position in the community. Although John has not been at this current job for an extensive length of time, he has been working at regular jobs in the community for many years. Work plays a prominent role in John's life. It is his tie to the community; the real world.

Employment in a regular job in the community provides John with an escape from the consumer/survivor world: the system, the people and the illness. Work is a powerful entity that gives John the motivation that he needs to get up in the morning. For John, this reason to get up is an integral part of feeling good about himself.

> [I work] just to feel better about myself...Everybody needs a little self-esteem. You know, a reason for being alive, I did it for ten years, laying on my side eating chicken, drinking beer and watching T.V.

For John, the influence of work on his quality of life is so substantial that he insists on working despite of the difficulties that it sometimes presents. Because he receives disability benefits, employment has not necessarily put John any further ahead financially and has, at times, negatively affected his mental health:

> I can make $160 a month, and after that, I keep 25% of what I make. So, it is, I am really not working for that much money. Like, when I could just be sitting on my pension. I think so far, it has been costing me to go to work, because I have to be there at 5:30 in the morning, and after a couple days of stomping back and forth to work on my feet, I take a taxi a couple of times, eh. And that just eats up the profits from working.

The pressures that often accompany employment in the community have, at times, resulted in near relapses for John:

> My first four days working [at this job] I got five hours sleep. Anxiety and stuff you know, going on in my life, that I just couldn't sleep. I was

> just about ready to go back to the hospital, but then I got three days off, and I just drank myself to death to get over it all and to get some sleep.

Despite these obstacles, John continues to see employment as a positive element in his personal recovery. John places a considerable amount of weight on the fact that his employment is in no way connected to his psychiatric disability. No one at work knows of his psychiatric background and he does not receive any special accommodation. John describes the aggravation and disenchantment he felt over a situation where he felt that he had been identified as a consumer/survivor:

> I had one job all sewed up, and [the supportive employment worker] spoke up and she was at the interview with me, I forget her name and everything, but she spoke up and mentioned that she would be around to help out, but they never called me back. Like she was talking with the chef and the manager, we had an interview going there and like the worker was with me. And he said something like…$6.50 an hour I guess, and the chef spoke up and said $6.75, like this and I was hired. But she spoke up and said, well, if there is any problem I will be around to help out…it took a few days to realise that they weren't calling me back.

John experiences a sense of isolation from both the "real world" as well as the consumer / survivor community. John wants as little as possible to do with the consumer/survivor community. He feels that the only way to ensure that his whole life is not contained within the walls of psychiatric disorder is to separate a part of his life from anything at all that has to do with his illness. John fears that being around other people with psychiatric disabilities will bring him down and his life will become stagnant:

> I try to keep away from psychiatry, like in [the group home], I was always depressed just from the fact of being there, it didn't do any good for me. I have seen people [with psychiatric disorders], they just sat there, they don't do nothing, just sit and stare at the walls...they'd be better off back in the hospital.

John experiences a general sense of unease around his involvement in the consumer / survivor community. John feels that his own mental health is often a lot to handle and he doesn't find much comfort in being around others with problems as he feels that in some ways he would have to deal with their problems as well as his own:

> I just don't want to be too associated with them because you never know what is going to happen with them. Like a friend of mine, like he stabbed himself in the side with a four inch blade, and you know, just if he did it to himself, he could do it to me. Like I said, I try to stay away from them...The psychiatric patients are actually quite intelligent and would know how to do a con job on you really easily, and you are dealing with unbalanced people. I'm a little unbalanced myself and I don't need to be with somebody else that is, that's why I say, I try to stay away...

There is a resentment that exists around having to deal with other people's problems in addition to his own. He senses that the consumer/survivor world is somehow removed from the "real world," that it is a world where the rules are different and things are easier. He doesn't want to be kept in a world that coddles him, or where people don't take responsibility. He fears that if he were to become too involved in the consumer/survivor community there wouldn't be any challenge left in life and he would become depressed:

> You meet people in these programs, and it is like an artificial life, and you get, if things don't work out and as an easy way out, like getting divorced or something, they say, well, it wasn't me, it was the program...you know,... so I back away from any of that.

John wants to feel integrated into the community but he feels that he must hide a part of himself in order to be accepted. John feels that if people were to find out that he suffers from a psychiatric disorder they would "tease me or maybe try to thump on me or something. They are angry because they are not getting $930.00 a month for watching T.V., you know". John spends the majority of his time at work interacting with non-consumer / survivors. However, when he is off work he fills his time with solitary activities such as "watching television" or "going to the bar." John doesn't socialise outside of work other than for "necessities."

Although he hides a part of himself in order to be accepted, this segregation of parts of himself also leaves John feeling isolated from society. *It is as though no one really* *knows who he is*:

> I didn't want anyone at work to know that I'm a shrink patient...[but] if no one knows much about you, you are still within yourself and in an isolation situation...there is the odd sole that I can talk to, maybe four or five, different people that, you know, I can be honest with about myself.

On the one hand, John says he doesn't want to be a part of the consumer/survivor community and on the other hand he says that in many ways it is less intimidating, fewer expectations, "I wouldn't look as bad." The consumer/survivor community is like an artificial world where everything is made easy. When John is in this world he doesn't feel that he has to hide part of himself. He feels good about this, but it feels uncomfortable knowing that he is not being held up to the same standards and expectations that exist in the "real world". This makes him feel as though he is not a "real" person and he feels useless. John is very confused about the idea of community integration. He feels that he is living on the periphery of both communities. John would like to be fully integrated into society but he feels that this can only happen if he can reveal all of himself. Unfortunately, John feels that the part of himself that he hides will never be accepted, so he continues to hide and as a result ends up feeling isolated from both communities.

John's major goal is to "get ahead financially." John's level of income affects his daily life in many ways, one of which is his access to medication:

> What happened was like my medication, like I ration it out so it come right to the end of the month when I got my cheque so I could afford to pay the user fee. That was at the MS but, it just kept slipping back, getting to the 25th when I needed it again, I didn't have the money and...D at the MS said that's okay, pay me at the end of the week, or at the end of the month, whatever...Now RMNE absorbs the user fee and I get it whenever I need it.

Choice is something that John doesn't feel he has a lot of within the structure of ACT. The professionalisation of staff roles gives John the impression that ACT providers know more than he does regarding his illness and his needs. John feels that if he were to disagree with his case manager or his psychiatrist he would "probably give in...like these people are supposed to know what they are doing, and you know...but then they are only human too, they can make mistakes." John feels confident, however, that the staff are in a position to make the best decisions for him.

Individual Structural Description: John

The underlying structure of John's experience of ACT can be seen in his conceptualisation of ACT as an entity that addresses his basic survival needs: medication and self-maintenance. These are areas where John feels that if he were to fall off track it would jeopardise his quality of life. *John does not want ACT to address anything more than his basic needs.* John views his association with ACT as necessary and productive within a particular sphere of his life. Outside of that sphere, however, ACT taps into John's fear of dependence and stigma. As a result of this fear of the negative impact of being associated with the mental health system, it is extremely important to John that ACT is kept as a small, separate part of his life. John feels that if he were to become more involved with ACT he would have to give up his independence. He fears that he would have no decisions to make and that his world would become devoid of responsibility. For John, this would mean his life would have no meaning and that his main purpose in life would simply be to exist.

Stigma is another issue that John closely associates with ACT. *John strongly senses that the part of his life that is associated with mental illness would not be accepted by the larger society.* John feels that the existence of stigma in the community is very strong. He feels that most individuals in the community would not have compassion for someone suffering from a psychiatric disorder. Consequently, *fear of stigma has forced John into a life of fragmented realities.*

So long as John feels that he must segregate a part of himself from society, he will live his life in isolation. The only place where John feels that he would be completely accepted is within the consumer/survivor community. He feels that there would be fewer expectations on him and that generally he would fit in better than he does in society. Overall, however, John doesn't feel any more comfortable within the consumer community than he does outside of it. The consumer community functions as a black hole, ready to envelop John if ever he lets his guard down: *he must constantly fight to avoid being consumed by a life defined solely by a psychiatric disorder.* The people, the issues, the workers, the entire community exists for one reason; illness. John wants his life to be about more than just mental illness and he resents the people who envelop their life within the mental health system.

John's sole means of participating in society is his work. Work is the one place in John's life where his illness is not the prominent focus. It is a place where he is seen and treated as a "regular" person. For John, it is extremely important that there be a part of his life wherein he can function as a "regular" person. Where the expectations and rules placed on him are the same as those placed on other people in society. It is at work where John comes closest to feeling normal, accepted and well.

John trusts that his case manager and psychiatrist will make the proper decisions regarding medication and other basic services on his behalf. There is definitely a view of ACT staff as the "expert." John is comfortable with leaving decisions regarding medication and other basic services such as domestic maintenance up to his case manager and psychiatrist. He doesn't question their judgement because he sees them as professionals who know more about these issues than he does. It is as though John sees individuals in the "professional" role as infallible or flawless.

The larger systemic issues that surround financial restitution for psychiatric consumer / survivors influence John's ability to make choices in a variety of ways. John feels restricted by the financial limitations placed on him as a result of receiving a government subsidy for disability. The government subsidy, as a financial entity, does not encourage individuals with psychiatric disabilities to earn money outside of this allowance. John works because he finds personal meaning in doing so, but in his own experience John does not benefit financially. Poverty robs a person of choice, and illness takes away any choice other than poverty. Because John feels that there will always be a danger of his illness manifesting itself to a point where he can not work, John doesn't feel he can afford to turn down the government subsidy he receives each month. The cyclical nature of John's illness, however, ensures that he will also have many periods where he is well enough to work but will never be able to produce financial gain. The poverty that John lives with affects his choices regarding where he lives, when he can afford his medication and what he does for entertainment.

In summary, John sees the world created by the mental health system is contrived, consisting of manufactured rules, expectations and responsibilities. As John sees it, individuals who live in this world don't actually have an easier life as a result of this artificiality; instead they become beings devoid of substance, vitality and vigour. John feels an ever-present need to separate himself from the mental health system and the consumer/survivor community in order to ensure that he does not fall into this way of life. Yet, at the same time John feels a very strong need for the safety net that ACT represents around medication and personal health.

Individual Textural Description: Sylvie

Sylvie is 31 years old, she lives with her non-consumer boyfriend in his home in downtown Kingston. Sylvie and her boyfriend have been together for nine years. Sylvie was born in Quebec but has lived in Kingston since she was 13 years old. After completing high school, Sylvie attended the fine arts program at the University of Waterloo. Sylvie dropped out of the program after two years and moved back to Kingston to attend the fine arts program at St. Lawrence College. In 1991, Sylvie switched from the fine arts program (she had been in the program for two years) to the nursing program where she met her boyfriend. Sylvie graduated from the nursing program in 1992 but has chosen not to pursue a career in nursing as her boyfriend feels that the field would be too tough on her. Currently, Sylvie is seeking employment as a secretary. Sylvie has been with the CIP program for one and a half years after being diagnosed with schizo-affective disorder (schizophrenia with a mood component). Sylvie has never been institutionalised in a psychiatric hospital. The interview with Sylvie lasted approximately 45 minutes. Sylvie was very happy to participate in the interview. The interview was conducted in the home she shares with her boyfriend. Sylvie was able to articulate her thoughts and feelings about ACT very clearly. Sylvie required some prompting after the initial open-ended question.

Sylvie's connection with ACT makes her feel special and important. She likens this experience to that of visiting a dentist in that someone is there to pay attention to and address her needs. The exclusivity of the situation makes her feel valued. The fact that someone is paid good money to address her needs must mean that she is important and that her needs are of significance to someone else. Sylvie feels valued by this experience and feels as though she is respected by the ACT team:

> [Being a client of ACT] means you are not just a patient, you are somebody

> special and they think of you as someone that deserves respect and that… they treat you like a person, they don't think of you as lower than them, they think of you as their equal.

Sylvie sees the purpose of ACT as being primarily related to medication. Sylvie's needs around medication are complex and involve more than just access to a prescription. Most importantly Sylvie feels the need for help in ensuring that she follows her medication regimen and doesn't "slip up." Sylvie is particularly fearful that she may "slip up" in this regard if she did not have some type of aid. "I go there every Tuesday and get pills and like you know, you meet people and that, it is nice." The intent of ACT is to provide structure or form to the lives of people with a psychiatric disorder who may need help in organising aspects of their lives:

> I think [the purpose of ACT] is to help control people a little bit more, like so they have something to do or whatever. Like some people look forward to going in there and working in the factory…just like the money and that, people with money, they have a little bit of money there and they have a little bit of spending money there, I don't, but a lot of people have spending money there and it helps them so they budget a little bit more, helps them budget.

Sylvie's conceptualisation of ACT encompasses the relationship that she has with her psychiatrist and her case manager. For Sylvie, the relationship with the psychiatrist is important; it is her tie to her medication. It is the relationship with the case manager, however, that holds most importance. The *case manager serves as the link to ACT*. It is this person who maintains regular contact with Sylvie, who is most familiar with Sylvie's life and *who relates to Sylvie as a friend*:

> [I see my psychiatrist] maybe once every five months, or once a year… [my relationship with my case manager] is like a friend. [I see my psychiatrist] once in a while, whenever I need a change in meds or something like that.

The support that Sylvie desires from ACT focuses on issues around her medication. Sylvie prefers very intensive support when it comes to her medication regimen. She has actually moved from a less intensive to a more intensive approach which has provided her with a significant sense of reassurance. Sylvie describes the support that she receives around her medication as one of her best experiences with ACT:

> When [ACT] started giving me the pills…I didn't have to go to RMNE all the time because it was always closed when I went down there. The best idea was that I pick up my pills [at the ACT program], because I wouldn't have to worry about it…It was nice for them to fill [my pill dispenser] because I wouldn't have to do it. Like I do it when I go down there, but it is like nothing, but if I had to do it by myself, I might slip up or something.

Sylvie doesn't wish, however, to receive other supports from ACT. She is quite determined to fulfil her other needs and to pursue her life goals without the support of ACT. For the most part Sylvie's needs are filled outside of ACT primarily by her boyfriend. *Sylvie is integrated into the community through her boyfriend.* She lives in her boyfriend's house, shares his friends and receives encouragement from her boyfriend to pursue work and education. "Like I already have friends [in the community]...they come here. Yah, like friends of my boyfriend and me...my boyfriend and Tommy [give me support]." Whatever Sylvie does accomplish on her own without the support of ACT is a source of great pride. There is a sense that pursuing these things independent of ACT is good for her.

Sylvie's relationship with her case manager is important to her. It is this relationship that links Sylvie with ACT and through which her needs are met. Sylvie relates her relationship with her case manager to that of a friend. She does not, however, consider this to be her closest relationship as she feels closer to her boyfriend and her own friends; "they are closer than [my case manager]." Sylvie considers her relationship with her case manager as one that occurs on an equal footing. For Sylvie, *the most important element within the client - case manager relationship is respect*, a sense that you are valued and the case manager does not feel that she / he is somehow above the client. "I think respect [is important], like not thinking you are lower or higher, like just equal...equality...we are both just as capable of doing something." Sylvie describes her worst experience with ACT as a time when she felt as though her case manager did not treat her as an equal. Sylvie felt as though she was being treated like a patient. This incident made Sylvie feel isolated from the case manager: as though all of the rules had changed and in that moment she no longer knew her own role within the relationship:

> [My worst experience] would be when [my case manager] mumbled one time. She said, "ah, do whatever you want," like that, like sarcastic

> or whatever. Yah, that was the worst...she just treated me like a patient for about 10 minutes.

Although Sylvie's relationship with her case manager is important to her, *the relationship that she shares with the ACT program is most important.* Sylvie comments that, if given the choice, she would stay on with CIP rather than follow her case manager, in the event that her case manager switched to another team in the area. She feels a certain comfort with the program and a familiarity with the other staff members. "I'd stay with [this ACT program] because I see a lot of people that I am familiar with I'd like to stay...I get to know the staff, they are really nice."

Sylvie is acutely aware of the stigma that exists towards individuals with psychiatric disorders. Consequently, *Sylvie doesn't feel as though she can allow other consumer / survivors to play a part in her life.* She feels that were she to be associated with other consumer / survivors she would be "painted the same colour" by members of the community. Sylvie is intensely fearful of the repercussions of stigma from the community. She refuses to be associated with other consumer / survivors and is both supported and encouraged in this decision by her boyfriend:

> All of my friends are [non-consumer / survivors]. Cause, like my boyfriend doesn't want me to hang out with them. Because he doesn't want me to be classified, sort of labelled cause they, when you hang out with one person, you are painted the same colour as them. So all of my friends are outside, in the community.

Sylvie's impression of how psychiatric consumer / survivors are viewed by the public is quite severe. She likens the hypothetical experience of being on a consumer baseball team to that of being on "a team of whores." In Sylvie's view consumer / survivors are rejected outcasts of society often looked upon as the lowest of society.

Sylvie feels that all consumer / survivors should be "integrated" into society; that they should make their lives as normal as possible, to ensure that they don't "stand out" from other community members both in terms of their individual behaviours and in terms of associating all in one group:

> It is good for everybody to have [consumer / survivors] integrated. Like my boyfriend says like there is this one guy that used to go to [ACT] and he still does, but he is looking better now, he's got a good coat, nice clothes on and [my boyfriend] says, 'good for him.' It is good for everybody if people are not so stand-outish. I just saw a group home down the street, and like I wouldn't want to live there. Cause like, I don't know...it is something that I don't want to get into.

Sylvie also expresses concern over being around individuals who may have experienced institutionalisation. For Sylvie, the idea of associating with consumer / survivors who have been institutionalised at various points in their lives is quite frightening. There is a sense that they may have needs beyond what Sylvie is willing to deal with:

> It is like, they all talk about the hospital, and it scared me away because

> some of them lived in the hospital, it scared me. Scared me a lot. There's nothing wrong with them…it is just something that I don't want to get into. It is something that I don't want to be a part of.

Sylvie describes her best experience with ACT as the annual summer picnic that is put on for the entire program including all clients and staff. For Sylvie, the importance of this experience was the joy that she received from participating in and watching others participate in activities. Sylvie really felt that everyone enjoyed themselves, which made it enjoyable for her. "I'd have to say the picnic [was the best experience]. [I liked just seeing] a lot of smiling faces." Yet fear of stigma and her boyfriend's disapproval keeps Sylvie from joining other outings with the ACT program. "I don't really want to go…I'm trying to get, like I am trying to get a job. [The picnic was good] for them…it makes them happy."

Choice is something that Sylvie feels she has a lot of in her life. She feels that she makes the decisions that affect her daily life independent of ACT and this is a source of pride for her:

> I think I have 100% choice I choose to be with my boyfriend…and I have a choice to live here…I have a choice of what field of work I want to do, and I have a choice of hair colour, I have a choice of how to wear [my hair]. I can wear it whatever way I want. And I have a choice whether I want kids or not, and I have a choice of names…choice of what I want for supper. I

> have a choice of whether to smoke or not...[today] I decided to visit [a friend]...and I decided to go to the [day centre] and I decided to do the dishes.

Sylvie does not feel that ACT or her case manager take choice away from her in any way.

> My [case manager] does not control my life or anything like that, she is good with that...she just does my pills. But once in a while, we go for coffee and get to know each other...she doesn't have any rules or anything like that.

Sylvie is also quite content to leave choice regarding medication up to her psychiatrist. She trusts his judgement completely and does not question it.

> [The psychiatrist] decides how much [medication] there is, and I am happy with what he says, because he is the doctor, not me...I trust him with my life...because he is older. He is old enough to be my grandpa and I trust the older people.

Sylvie's goals are very much in tune with white middle class values; a house, two children, two cars, and a supplemental income of $25,000 a year.

> I want to be a secretary on a computer and stuff. In personnel or something like that, like interviewing people...Two kids...we will probably live in the country...we will have two cars...[I would like to be making] $20-25,000.

Sylvie feels very strongly that she wishes to pursue her goals on her own without the assistance of ACT. The most that she sees that ACT could do for her around her goals would be to provide her with "connections" for work and education. For the most part, Sylvie feels that she has enough supports outside of ACT to help her achieve her goals. One of Sylvie's goals is to move on from ACT. Sylvie, however, is still very tied to ACT and as a result does not feel that she is ready to move on just yet. "I'm not ready to move on...I'm still on the pills, so I have to get my pills...I think you have to have a psychiatrist, because they are psychiatric pills."

Sylvie believes that it is important that ACT provide more opportunities for activity within the program. She believes that this would be important as the few times that she has participated in program activities she has observed how important the outings are for clients, "[I think there could be] more outings for the clients, like maybe more picnics...hiking and swimming, like maybe go to Picton beach once in a while...yah, for the people, for the clients, just [to see] the smiles on our faces."

Overall, Sylvie's need for ACT stems from her needs around medication. Although tied to ACT as a result of this need, her fear of stigma fuels a concerted effort to disassociate herself from the program and the consumer / survivor community as much as possible.

Individual Structural Description: Sylvie

The underlying structure of Sylvie's experience with ACT is expressed in her conceptualisation of ACT as a service that is provided to meet her needs around medication.

Sylvie's psychiatrist represents her tie to her medication which she sees as the primary reason for her relationship with ACT. Sylvie holds her psychiatrist in high esteem; she regards him as an expert and trusts him completely, even though she meets with him on a fairly infrequent basis. *The case manager, on the other hand, fills the role of a friend for Sylvie.* The case manager is important because she is the person who is most available to Sylvie and with whom more time is spent but is not held to quite the same degree of "expert" as the psychiatrist.

It is extremely important to Sylvie that she be seen by her case manager as equal. Sylvie describes her worst experience with ACT as a time when she felt that her case manager treated her like a 'patient.' The interaction was quick, curt and devoid of tolerance and patience. As Sylvie associates personalised attention with respect, she felt extremely disrespected and devalued within the context of this interaction. It is interesting that Sylvie associates this specialised or personalised attention with feeling like she is not being treated as a patient. She associates being treated like a patient as not receiving personalised attention, of being ignored, of not having anyone to listen to her needs, of not having any time for her.

Although there is a part of Sylvie that seeks social opportunities with other clients, there is an even larger part of her that completely rejects the consumer community. This adamant rejection in light of her enjoyment of social activities with clients of ACT, speaks to a fear of stigma. Sylvie is convinced that were she to display her connection to the psychiatric community in any way she would not be accepted by people in the community. Sylvie experiences great concern over the level to which she is accepted in the community as this acceptance is tied very closely to the quality of life that she experiences. Her life is tied to individuals without mental illness who she fears would look at her differently were they to see her as a consumer. Sylvie's boyfriend, who is aware of her connection to the mental health world, stresses to her the importance of not associating with other consumer survivors; of looking and acting "normal" at all times. It is this intense fear of rejection from both the community and her boyfriend that accounts for the contradiction that exists in Sylvie between finding enjoyment in socialising with other consumer / survivors and at their same time likening this experience with being forced to deal with the ridicule that one would incur were they to associate with individuals labelled as whores.

Another issue that presents a barrier for Sylvie around her association with the consumer/survivor community is the level of discomfort that she feels with individuals who have been hospitalised. There is a fear of the unknown: that other consumer / survivors are somehow unstable or dangerous, that their experiences with psychiatric disorders are somehow different from hers. Sylvie sees herself as different from other clients who have been institutionalised and her lack of knowledge about their experiences becomes a source of fear and ultimately rejection of this group.

Although Sylvie looks outside ACT to have her needs met, Sylvie's main support system outside of ACT lies primarily with one person: her boyfriend. Sylvie is dependent on her boyfriend for a home and friends. As a result, the question arises as to whether Sylvie truly experiences independence or whether she simply has an alternate support system upon which she depends.

However, the choices and decisions that she makes occur around her basic everyday needs: food, appearance, socialisation and housework. Decisions and choices that affect higher order needs such as employment, education and medication are usually made in conjunction with others and in some cases Sylvie seems to defer entirely to another person. Issues such as work, education and who to associate with are greatly influenced by the opinions of her boyfriend. Sylvie places great trust in her boyfriend and seems very unwilling to make a choice that he might disapprove of. Sylvie is equally trusting of her psychiatrist and she considers him an expert regarding psychiatric medications. She defers all decisions regarding medication to her psychiatrist. For Sylvie, the thought of questioning either the decisions of her psychiatrist or her boyfriend is unthinkable.

Sylvie feels that she has complete choice in her life but is gravely unaware of areas of her life in which she could have more choice. Sylvie has also not been informed about how to receive services around medication outside of ACT. This information would be valuable for Sylvie to have when weighing whether or not she will move on from ACT. This lack of information regarding the system also takes away choice and leaves the decision of when to move on from ACT in the hands of other people.

<u>Individual Textual Description: Pat</u>

Pat is 46 years old. She was born and grew up in Kingston. Pat became pregnant at the age of 15. Shortly after the pregnancy Pat became ill and was hospitalised at the age of 16. She was diagnosed with schizo-affective disorder (schizophrenia with a mood component) and in more recent years has also been diagnosed with a substance abuse disorder. Pat became pregnant again in her early thirties. This child is now 13 years old and lives with her adoptive family in Gananoque. Pat has been able to keep in touch with her daughter who she sees on a periodic basis. One of Pat's goals is to re-gain custody of her daughter. Pat has been in and out of hospital on a very frequent basis over the past 28 years. She has lived with her boyfriend, another member of the CIP program, in an apartment in downtown Kingston. Pat works in a sheltered workshop program run by the Kingston Psychiatric Hospital and is looking to move to a supported program in the contract factory where she would make more money. Pat has been with the CIP program for the past eight years. The interview with Pat lasted a total of 50 minutes and took place over two visits. Pat stated that she was nervous during the interview. She smoked a lot during both interviews. Both interviews were conducted in Pat's home. Pat appeared very shaky (her hands and legs kept shaking) during the interviews and I wondered if this was due to the side-effects of the medication that she was taking. Cognitively, Pat seemed to loose her train of thought easily and frequently. She often wanted to change the subject to talk about something else. During the second interview Pat seemed very distant and distracted. I am not sure if this was due to symptoms of her illness or again due to side effects of the medication. Pat answered my questions but not to the same extent or with the same clarity as she had in the first interview. Generally, I found that it was more difficult to get at the meaning of the experience for Pat and I often had to re-word questions.

Pat's primary association with ACT is with regard to medication. She feels that she is tied to ACT for this reason and could only ever leave ACT if she found a replacement for the services that she receives around medication. For Pat, ACT essentially means a place where she goes every two weeks to receive an injection. "[ACT] means I go in for injections and they talk to me. [ACT] helps us out like, you know...I got bad nerves eh, so, I get injections eh, every two weeks." Pat feels that she has someone with whom she can talk to about things that may be bothering her in her everyday life particularly around issues of medication. "They talk to us...whatever is bothering me. I see [my case manager] mostly. Sometimes I see my psychiatrist when something is bothering me eh? Like if I can't sleep or my nerves are bad." Pat views her experience with ACT as very different from her experience in the hospital. "I definitely feel part of the community, not part of the hospital, I don't want to go back in [the hospital] as long as I live."

Pat looks to ACT to provide her with fairly intensive support around medication. She receives injections every two weeks as administered by ACT staff. Pat feels very reliant on staff to provide this service and feels that this type of support is extremely important in her life. *Pat also receives support from ACT around other areas of her life including work, education and social activities.* Pat relies on ACT to provide her with a tie to opportunities to work in supported employment offered by outside agencies. Pat has a strong desire to work, to have something to do and to earn extra money. She is very happy that she has received support that has connected her to an opportunity that provides both activity and extra money:

> I am trying to get into [occupational therapy] right now, eh. Where I knit

> things, knit like scarves and hats and mitts and slippers...Like they have separate workers, special [occupational therapy] workers that do the knitting and crocheting. [My case worker] helped me get into the program. She suggested it to me. I would like to work at the ...contract factory. They work with nylon and that, eh. I'd be bringing in the nylon and putting it on the machines...I'd just like to, mainly because of the money, it is not bad, eh. But if you make extra, they deduct it from your cheque, eh.

For Pat the most important aspect of being hooked up with an occupational therapy program is to gain extra money. She is unclear as to which program to pursue; contract factory or knitting. For Pat, the actual activity is not the point as much as it is simply to have activity and the opportunity to earn extra money.

Outside of areas that concern medication and work, *Pat receives her primary support from her boyfriend and his family*. "[ACT] doesn't help me with all that much really." Pat relies primarily on other people in her life for much of the support she receives. Pat socialises with her boyfriend and his family:

> We go grocery shopping every Tuesday, S's mother takes us. S and his brother, yah, they are good friends. S is my boyfriend but we are also friends. I talk to him when I got problems and that. And he helps me out by saying something to the staff or something, if something is

> bothering me or something. S's mom, I talk to her quite a bit. Pretty well everyday she phones yah, I talk to her. I do bar-be-queues and that with them, with S, I go with S's relatives.

Pat's case manager has linked Pat up with education, and drives her to see her daughter. There are areas in which Pat feels that she could receive more support from ACT. She has some difficulty, however, conceptualising exactly what form this support would be provided in. Although she would like help from ACT she is not sure exactly how they could help. Pat experiences difficulty conceptualising what she could get from ACT around her goals. The type of support that Pat envisions that ACT could provide her with takes the form of having someone do something for her. For example, Pat's suggestion for support around education would be to have ACT "put me in a course" or let her "make long distance calls" to facilitate a closer relationship with her family or have her case manager "help me find a place" and take her "down grocery shopping' so that she could live on her own.

Pat feels that she is integrated into the community; that the community welcomes and accepts her. She describes her associations as having a few friends from the consumer / survivor community but that most of the people in her life are non-consumer / survivors. "A few friends [who] are ex-patients, S is an ex-patient, but most of [my friends] are out in the community." Pat feels that it is best for psychiatric consumer / survivors to associate with non-consumer / survivors so that they are exposed to the way things are done in the 'real' world. For example, Pat's reaction to the question of whether it would be better to design a baseball team for consumer / survivors or to involve them in an integrated team was this "[A] mixture [would be] better for the psychiatric patients…because they get to learn how to play the ball game right." However, Pat feels that some consumer / survivors will never be able to live in the community on their own:

> Some will have to be locked up forever, you know. They are just too messed up…[you] can't let them run around the streets like that, half undressed and you know, the way they act and that. [When I was in the hospital] I saw people…half dressed, you know, it was horrible… and they will be in there the rest of their lives.

Pat sees a certain section of the consumer population as being unable to live in the community and sees herself as different from them. "Like, I don't have serious mental illness where I have to be locked up or anything, I'm just kind of slow and not quite as afraid as some of the others."

Pat considers her relationship with her case manager to be very important. It is important to Pat, that she feels comfortable with her case manager and that she has a friendly relationship with her.

> I have a pretty good relationship with [my case manager]. It is pretty important…so I can talk easier, talk better with her…a little more comfortable. I see [my case manager] as a person, she is friendly and that, and she is kind hearted.

Pat considers her relationship with her case manger to be more like that of "a friend." Pat's goals for the future include creating a closer relationship with her daughter who has been adopted by a local family, finding work, pursuing more education, forming closer relationships with her family and quitting smoking. The goals that hold most importance for Pat are finding work in the contract factory, getting custody of her daughter and quitting smoking. Pat feels that work in the contract factory would help fill some of her needs around money. Pat is aware, however, that even if she got a job with the contract factory she would still face monetary issues that come with being on a disability pension:

> I'd just like to work [at the contract factory] mainly because of the money, it is good money, it is not bad, eh. If you make extra, they deduct it from your cheque, eh…at one time I was going to get off the pension, eh, yeh, maybe work outside in the community, I thought that'd be better you know, actually, but I know I am still here though.

Of these goals, Pat's case manager has provided support around helping her quit smoking by providing her with the antismoking drug Zyban and has also driven her to see her daughter.

Pat is quite pleased with the amount of choice that she has in her life. She cites many decisions that she makes regarding everyday activities in her life:

> One thing, in the morning [I have a choice of] getting up out of bed…and

> when I listen to the television or radio that's one of my decisions, whether I want to eat or not. Whether or not I want to have breakfast, or lunch or whatever, supper. Sometimes I only eat one meal a day, eh.

Pat feels she is the prime decision maker over many issues in her life such as the decision to enter hospital, take her medication and decisions around her daily routine. "Yah, like nobody pushed me into coming into the hospital, I just signed myself in, eh. You know, like, nobody forced me into it or anything. So, I think I have a lot of choices." Pat also feels that she has choices around her medication " I don't really have to be on it if I don't want it. I don't have to be on medication." *Issues regarding money, however, are where Pat feels that she has very little choice and control.* Pat related an incident in which she disagreed with her case manager and psychiatrist around money:

> I wanted money. They didn't seem to want to give it to me. Well, like something I wanted. Usually, I do get it though, but not all the time, I don't get it as much as I like, because, like they are trying to make a savings account for me, eh. They are trying to save my money… I get discouraged, a little bit upset but there is nothing you can do about it, eh…I lied about trying to get some extra money or something, and it didn't work out, I got caught in my lie, they weren't pleased, they were mad at me. Ticked off at me, eh, because I was lying to them…they wouldn't give me the money.

Pat describes her best experience with ACT as the annual summer picnic. She enjoyed this experience for the opportunity for socialising and activity it provided. "[The best experience was] the picnic, in the summer time we go out to the lake. [I like it] because they all have fun. We go swimming and we play volleyball, or something and then we sit around talk and eat food...sometimes we sing, sit on the bus and sing something."

Individual Structural Description: Pat

Pat's perception of ACT is based first and foremost upon the services she receives around medication. The injections of medication that she receives on a regular basis are the first thing that comes to Pat's mind when she is asked about the purpose of ACT. Pat is aware of other services that exist within ACT and are offered by her case manager, for example, having her case manager provide her with access to a vocational program, or receiving support from her case manager to quit smoking. However, when asked whether or not she would follow her case manager to another program, Pat's largest concern is whether or not she would retain the services that she currently receives around medication. This concern indicates the amount of importance that Pat places on the services that she receives around medication. Not only does Pat see medications as the primary purpose of ACT but it is also extremely important to her that she receive this type of assistance. Pat conceptualises ACT as primarily a relationship that she shares with her case manager and psychiatrist for the purpose of maintaining a medication regimen. Pat's primary contact is with her case manager and she often engages in activities other than those related to medication with her case manager. However, Pat does not view these activities as the most important aspects of her association with ACT.

Pat definitely conceptualises ACT as a different experience than being in the hospital. *Pat sees the experience of ACT as one that is in the community, one in which her case manager is her friend and one in which she is treated respectfully.* Pat's experience in the hospital, on the other hand, was predominantly a negative experience where she felt separated from the community.

Pat's primary goal for the future is to obtain some form of employment that will allow her to earn the 160 dollars a month that she is allowed to earn on top of the regular disability pension that she receives. Pat feels a requirement for extra money than she currently receives. She finds it difficult to afford her smoking habit and often finds that she is unable to afford social activities such as going to a movie with friends.

The support that Pat receives in relation to her medication is very intensive. This type of support is very outcome oriented in that it promotes the final outcome (Pat following her medication regimen) as opposed to the process (guiding Pat to figure out a way on her own.) Consequently, when Pat tries to think of other ways that ACT could help her in various areas of her life (work, seeing her daughter, etc.) she also conceptualises this type of help as outcome oriented (e.g., providing her with a ride to see her daughter, signing her up for a course, or finding a vocational program for her). Pat does not conceptualise a process oriented approach to receiving services from ACT. As a result she is unable to ask for a different kind of support that may be more conducive to her gaining skills and independence.

Pat's integration into society is limited primarily to her boyfriend's family. Her own family is quite distant from her (both physically and emotionally) and she has a daughter who now lives with adopted parents who she sees on an infrequent basis. She socialises primarily with her boyfriend who is also a psychiatric consumer/survivor. Pat sees her associations as consisting of a mixture of consumer / survivors and non-consumer / survivors as her daughter and her boyfriend's family are not from the consumer community. *Pat comments that she does not participate in many social activities in the community due to a lack of money.* Pat sees her relationships with consumer / survivors as individuals who aren't socialised in how to do things the way that things are done in the "real" world and who could benefit in this way from opportunities to interact with non-consumer / survivors.

Pat does not see the time that she spends with her case manager as necessarily time that she is receiving services other than when she is in for her injection. Pat's experience is that she is spending time with her case manager chatting. For Pat, her relationship with her case manager is not as important as being a client of ACT; the most important aspect of ACT for Pat is that there is a structure in place for her to follow her medication regimen.

Pat experiences choice around her daily activities such as; meals and viewing television. Pat also feels that she experiences choice around larger issues such as whether to enter the hospital or whether to take her medication. Pat doesn't feel that she experiences choice around issues of money, however. Pat often has difficulty accessing extra money that she may have as certain restrictions have been put in place by ACT in order to help Pat with her budget. Pat finds this experience frustrating as she experiences a loss of control over decisions regarding her money. Pat does not feel that there is anything she can do to override the rules set by ACT in this regard. She does not demand her money or leave the program as she is not aware that there are any other options.

Presentation of Group Data

In this section I present the data in a way that encompasses the experiences of all participants as a synthesised whole. The composite textural description depicts the way in which the group experienced the phenomenon. The composite structural description, on the other hand, describes *how* the group as a whole experienced *what* they experienced. Finally, the textural / structural synthesis provides a synthesis of both the composite textural and structural descriptions. In other words, a coming together of the meanings and essences of the experience for the whole group to present a complete picture.

Composite Textural Description

For each research participant ACT is experienced as a single relationship that exists between themselves and their case manager. There is also a recognition that there is a link between their relationship with the case manager to a psychiatrist who they see for medication purposes on an infrequent basis. The participants do not conceptualise ACT as an institution with an associated body of people working as an integrated infrastructure. Participants who have been hospitalised in the past perceive ACT as a resource for the many needs that arise when a person first re-enters the community. *The area that is seen to be of primary concern for all participants and the one that ACT is* *most prepared to offer support around, on a consistent basis, is medication.*

All of the participants in the study viewed their relationship with their case manager within the context of a friendship. In all cases this relationship was viewed as positive and close. In some cases it was perceived to be one of the closest relationships in the participants' lives. *The case manager is viewed by all participants as a friend*: someone who is easy to talk to, who will listen to their problems and who they spend time with socially.

Most of the participants value this relationship a lot and wish that they had other close friendships like this one out in the community. *Most participants feel a lack of friendship in their lives. They wish that they had more opportunities to form social relations either with other consumer / survivors or with non-consumer / survivors.* When participants describe the type of relationship that they are looking for, describe a partnership in which someone is interested in finding out about them. Most participants don't feel that they have this type of friendship in their life currently. Many of the participants have spouses or are living with a partner but still feel that this type of friendship is missing in their lives. Both the roles of the psychiatrist and case manager are seen as professional and expert. *For the most part, participants do not question the decisions made by either the psychiatrist or the case manager.*

All of the participants receive rather intensive support around medication. For certain individuals this support involves pre-arraigned, bi-monthly injections as provided by a staff nurse. For others, it involves ensuring that they get their monthly prescriptions by dispersing the prescription through ACT. Still others receive support in correctly filling their pill dispensers. Some participants receive various types and levels of psychosocial support in addition to the support they receive around medication. This support is typically experienced as less intensive and in many cases has been initiated at the suggestion of the case manager. *Types of psychosocial support often engaged in by participants are vocational and educational.* The type of support provided around these psychosocial areas often involves having the case manager enter the participant in an educational program at the local college or assist the individual in obtaining some type of supported employment designed for consumer / survivors.

Many participants expressed that they would like to receive further support around their personal goals for education, work, community integration, development of self-esteem and increase in social activity. Many of these individuals feel that ACT would probably help them with these goals but they have never asked for assistance in these areas.

Participants often conceptualise the type of support that ACT would provide in various areas as direct service. For example, they conceptualise the case manager as arranging a group for them to participate in where they would engage in social activities or where they would meet non-consumer / survivors. Participants do not conceptualise ACT as providing them with services in a way that would be more guiding. *For many participants, there is a strong desire to not let ACT provide them with supports other than those around medication.* These individuals experience a strong desire to be independent of ACT at the same time as they experience an equally strong desire to maintain fairly intensive support around medication.

The desire to be independent of ACT comes from several sources. For most there is a perception that being dependent on ACT is somehow unhealthy for them as individuals. A predominant experience is a fear that any link to ACT will result in a label which in turn will result in rejection from the community. Still others feel that ACT is simply not willing to provide services outside of medication, hence, the only way to achieve one's goals is independently. *For these reasons, individuals are more likely to pursue their goals around education, vocation and community integration on their own or with the help of individuals not associated with ACT.* Consequently, the results of their efforts are more likely to resemble a normalised picture. For example, all of the individuals who rejected support from ACT in finding vocational opportunities are either seeking independent employment or volunteering in an independent work setting, whereas, the participants who sought support from ACT around vocational opportunities are currently seeking work in a supported vocational program. Likewise, those individuals who refused the services of ACT outside of medication support are more likely to have a larger social network and also more likely to associate with non-consumer / survivors.

The goals that are most important to the participants are obtaining or maintaining work, building self-esteem and self-confidence, increasing the amount of income they have and becoming better integrated into the community. These areas are often goals in participants lives because they are areas in which they experience little satisfaction. *Participants experience a lack of clarity around how to go about developing and meeting these goals.* Some try to pursue these goals independent of ACT by applying for jobs through the common market. Others look to ACT to help them meet these goals and often become enrolled in supported programs designed for consumer / survivors. All of the participants expressed confusion about how to go about building self-esteem and becoming integrated into the community. *All participants felt that their lives were particularly lacking in these areas.* Some participants experience a desire to have ACT provide programs that address these issues, for example, a group designed to hold discussions on self-esteem or a group that encourages a mixed membership of consumer / survivors and non-consumer / survivors. These participants experience a sense of frustration that this type of support is not offered. Other participants feel that in order to achieve self-esteem they must hide any link to the mental health system. Participants experience an overall sense of frustration and despair that they may never be in a position to realise these goals.

All of the participants experience work as a top priority in their lives. For some individuals the priority is set around obtaining work and for others it is maintaining work. For many individuals work represents a way of putting meaning into one's life through activity. The largest benefit to work is the feeling of productivity. This is relevant whether the person is a volunteer, in a supported approach or in an independent position. The second most important aspect of work is whether or not the work is paid. Payment is seen as an acknowledgement that their work, and by extension that they themselves are valued by the community. Paid work is a symbol of acceptance and respect from society. Receiving a pay cheque is also valued as a way of providing oneself with extra money over and above the monthly allotment of the disability pension. Independent work is seen by all participants as the ultimate form of community integration, independence and separation from the consumer community.

Many participants feel frustrated by a lack of self-esteem. This lack of self-confidence is seen as a barrier to becoming integrated into the community, engaging in social relationships, and applying for jobs outside of the consumer community. There is a sense that if only ACT would provide them with the services to be able to build self-esteem and self-confidence they would be able to pursue goals around vocation, community integration, education and friendships independent of ACT. The participants who feel that they lack self-esteem and self-confidence look to ACT to provide them with services to address this need through some type of program.

Increased income is an issue for all participants. Each participant receives a disability income of approximately $900/mth. The disability income is a federal government subsidy for individuals who have been deemed unable to work due to a debilitating disability. For all participants this amount of income addresses basic needs such as rent, food, clothes and personal amenities. This amount, however, does not easily lend itself to pursuing activities that address higher order needs. Many participants relate the lack of social activity (movies, local theatre, joining a group) in their lives to a lack of funds left over after addressing basic need areas. Although two of the participants have profound smoking addictions that infringed upon the availability of excess money, all participants experienced a restriction in the degree to which they could pursue social activities. *These participants experience low income as a major barrier to pursuing opportunities that they feel would add meaning to their lives.*

All participants feel a need for income above the monthly allotment from the disability pension. Government regulation concerning disability pension states that any individuals who receive a disability pension are limited to earn $160/mth in addition to their monthly allowance from the government. Any amount earned over the $160.00 is deducted from the individual's pension. All participants desire the opportunity to earn the additional entitlement of $160/mth. Each feels that additional income would help her / him to pursue social activities such as going to the movies and going out with friends.

All participants experience the disability system as extremely limiting. Each feels that even if they were fortunate enough to acquire a paying position they would never be in a position to "get off" of the disability pension. Most participants feel that due to the temporal nature of mental illness (many individuals frequently experience extended periods of wellness between periods of illness) there are many periods in their life where they could be employed in the workforce. Yet, these periods may just as easily give way to periods of debilitating disability. Participants feel that the system robs them of the opportunity to be self-sufficient, to pursue paid meaningful activity at times in their life when they are capable of achieving this.

All participants feel that the most important aspect of community integration is the interaction with and acceptance by non-consumer / survivors. There is a general perception of the existence of two communities: the community at large and a consumer community. The consumer community is seen as being separate from the community at large, with its own set of rules, responsibilities and expectations. The participants view the consumer community as artificial: a place where the rules, expectations and responsibilities are fabricated by the mental health system. The community at large, on the other hand, is viewed as the "real world": a place where the rules, expectations and responsibilities are legitimate. In viewing the larger society as the "real world", participants are viewing the consumer community as a protective society in which the rules, regulations and expectations are easier for them. *For all participants the idea of becoming truly integrated into society through independent employment, independent housing and association with non-consumer / survivors symbolises true recovery: a reflection that they have what it takes to make it in the "real world."*

Although all participants have a strong desire to be integrated into the community and to live their life in the "real world", many feel a sense of safety and acceptance in the consumer community. The rules, responsibilities and expectations in the consumer community are perceived to be very tolerant, empathic and accommodating. In contrast, participants experience the rules, responsibilities, and expectations of the larger community as challenging and worry that they may not be able to successfully meet these expectations.

Many participants feel that it would be beneficial for them to be involved in both communities: to have the opportunity to both pursue the challenge of meeting the existing expectations of the "real world" and to be able to retreat to the consumer community when the challenges of the "real world" become too overwhelming. For other participants, the separation of the consumer community from the larger society is seen as a source of stigma and lack of acceptance of consumer / survivors by society. It is felt that by associating with the consumer community in any way (associating with other consumer / survivors or being linked with a mental health agency) ensures that they will not be accepted by members of the larger society. *Many of these participants feel that they have worked hard to achieve a level of acceptance within society with co-workers, partners and friends and, hence, are very fearful of losing this acceptance.* They feel that the people who they have formed relationships with will abandon them if they were to find out about their association with the consumer community. These participants feel that they have to hide a part of themselves in order to be accepted by society. Unfortunately this also affects how they feel about themselves. They feel as though only a part of them, the well part, is valued and accepted within society. The other part, the illness part, is not accepted or valued.

All participants experience a significant amount of choice around issues regarding their daily activities. They feel as though they are the primary decision maker regarding when they will get out of bed, what and when they will eat, when and what they will watch on television. *Participants do not experience choice in their daily lives around more complex issues such as the type and amount of medication they are on, the type of job they have, and how integrated they are into the community.*

Composite Structural Description

Structurally, *ACT is organised in such a way that it promotes an intensive relationship to develop between the client and the case manager.* As a result of the ACT structure, clients have little to no contact with other ACT staff except the psychiatrist to whom visits range from once per month to every six months. *The presence of a* *psychiatrist symbolises medication.* Any counselling that occurs between client and psychiatrist is around medication, hence the relationship with the psychiatrist is very much centred around medication. All clients receive different psychosocial services from ACT depending on their needs. In fact, the only consistent support provided across the group is related to medication and for some participants this is the only support they receive from ACT.

Participants conceptualise the type of help that ACT can give in the same way as the direct assistance they already receive from ACT around medication. ACT has a certain prescription for how they offer services, structured, in vivo, intensive and direct. Some clients reject ACT because they don't like the way the services are offered and end up inadvertently achieving a more normalised solution to their goals than if they had asked for ACT's help. *In other cases participants look for programs to address personal needs such as community integration and self-esteem. When these programs are not offered an anger builds toward ACT.* There is an essential lack of understanding that the way in which services are typically offered by ACT is incompatible with the pursuit of goals such as self-esteem, self-confidence and community integration. Participants experience frustration over a lack of clarity of how to address these issues outside of ACT. For some, this frustration leads to a rejection of ACT. It is this frustration that underlies a concerted effort to go about achieving these goals independently and in others this frustration festers and leads to a sense of hopelessness and helplessness that in turn fosters a further withdrawal from the community.

The intensity of service offered by ACT ensures that they are in contact with clients on a very frequent basis. As a result, most services provided by ACT occur in the community. When this theory is transferred to a transactional level, however, the end result is that much of the time spent between case manager and client occurs in coffee shops and in clients' homes. The majority of interactions consist of talking. Despite whether the case manager is assessing how a person is doing, what they have done in their day or how their medications are, to the client this interaction is perceived in a social manner.

The participants express their desire for friendship in a very one-sided way. Participants want someone to get to know them and to spend time with them but they do not, in turn, express a desire to get to know another person on an intimate level. *It is as if participants have not experienced a relationship based on reciprocity.* There is a lack of awareness that reciprocity is an integral part of a relationship. This relationship between client and case manager has elements of friendship but the danger is in creating a situation where clients think this is a real friendship.

Work is so important because it addresses so many needs in the lives of participants. Work is an opportunity to earn the extra money that they are allowed to earn on top of disability pension. Society places a value on earning a living and devalues "handouts" such as welfare and disability pensions. Participants are aware of this value system and feel somehow less worthwhile. They feel that they are a burden on society if they are only living on a "handout." Most participants place a lot of value on the activity that work plays in their lives; it gives them a schedule, a time to get up and a place to be. Getting paid is a symbol in our society of worth. The more something is worth, the more people will pay for it. Although volunteer work provides the activity and sense of meaning that are important to consumer / survivors; it does not provide a sense of worth from the perspective of the community. Consumer / survivors spend so much of their lives feeling isolated and not accepted by society that the need to feel accepted by society is very great. Payment for a service that they provide makes them feel as though they have something to offer that is valued by society and through this they sense a level of personal acceptance. Work, whether it is a supported position or an independent position, provides the opportunity for social interaction. *The majority of the participants experienced rather limited social networks; many craved the opportunity to interact with others on a social level. Work is seen as a primary way to facilitate opportunities to meet other people: a way to make friends and just be around other people.* Independent work provides the opportunity for a sense of community integration. To be performing the same work as non-consumer / survivors with the same role, responsibility and expectations brings about a sense of true integration often not felt in any other situation, a feeling of being normal and accepted, not a feeling of being "special" or different which is so often felt by consumer/ survivors.

Clients of ACT usually begin with the program after spending a period of time in the psychiatric hospital. When a person first enters the community from a stay in the hospital she / he often experiences many needs. *Most individuals do not have families or outside supports who can fully provide for all of these needs such as housing, income, access to medication, and support during crises. ACT does address these basic needs*, particularly those that are most pressing when one first enters the community after a period of time in the hospital. *For all of these participants, basic needs such as housing, medication, food and a connection to some sort of organised support had been provided.* With the exception of the continuous need for medication and crisis support the basic needs that participants had when they first left the hospital and joined ACT have been addressed. *What has not been addressed, however, are the needs that arise once basic needs have been accommodated.*

ACT places a priority on addressing basic physiological and safety needs. Consequently, needs associated with personal growth are addressed only peripherally. Because of the way that ACT is structured, however, clients only see one way to achieve these growth needs: to have it done for them by someone else. The very nature of growth needs (self-confidence, self-worth), however, ensures that the responsibility of pursuing and meeting these needs must lie with the individual. The approach for physiological and safety needs is very assertive and intensive, perhaps as it should be, and concentrates on giving the responsibility of the task to the provider to ensure that needs around medication and crisis are met. Unfortunately, however, it is precisely this assertive, in vivo, one on one structure that inherently creates barriers to the attainment of higher order needs such as empowerment and community integration. Higher order basic needs and growth needs cannot be met within the context of such a microscopic approach. Likewise, it would be difficult to address crisis situations through an approach designed to promote empowerment. It is here where the crux of the problem lies. By designing systems that place as their focus either an emphasis on illness or an emphasis on wellness, we are resolutely unable to provide an adequate structure to address the needs of the whole individual. Until we design structures that recognise implicitly the synthesis between both illness and wellness we will continue to fragment individuals through our approach.

Textural/Structural Synthesis

At the most primary level participants' conceptualise ACT as a singular relationship that exists between themselves and their individual case managers. This relationship is ever present and at the same time, ever changing, depending upon the nature of the interaction between client and case manager. The interconnected levels that occur within this relationship are grounded within the elements of friendship, support, professionalisation, choice and needs.

For the participants, *ACT is not experienced as it is defined in theory* (Test, 1981). It is not experienced, for example, as a structured multidisciplinary team of individuals coming together for the purpose of providing sustained and intensive assistance to maintain individuals with psychiatric disorders in the community (Test, 1992). Instead, participants possess a localised view of ACT. Their perception of ACT occurs at the level at which ACT immediately affects them, and is confined to a particular situation involving their relationship with their case manager.

> [ACT means that I see my psychiatrist] maybe once every five months, or once a year...[my relationship with my case manager] is like a friend. [I see my psychiatrist] once in a while, whenever I need a change in meds or something like that.

Although there is a limited awareness of an entity that extends beyond the relationship with the case manager, it is not fully articulated in the way a typical consumer would perceive a service: as an entity consisting of a multidisciplinary staff offering a range of services. Instead, ACT is viewed primarily as a singular relationship that both provides and links participants to a predetermined set of structured supports. "[The case manager is] the mirror, you know what is offered through them...because they are the first person you contact..." This finding raises the question as to the possible dissonance between the theory of ACT and how this theory is translated into practise.

Despite this relatively localised view of ACT, however, there is a point at which a dichotomy exists between the perception that participants hold of their case manager as their primary link to ACT and the responsibility which they place on this person for any dissatisfaction they have with the program. Most participants viewed their relationship with their case manager as an extremely positive experience. However, at the same time, most participants also experienced various levels of disappointment with ACT related to issues around the focus or intensity of support they received. The relatively obvious explanation for this contradiction involves the perception of the case manager as the primary tie to ACT. There is a reluctance on the part of the participants, possibly even an inability, to direct this disappointment at the case manager while concurrently perceiving this individual to be the link to existing supports. Consequently, although ACT is conceptualised as a singular relationship that exists between client and case manager, the client does not hold the case manager directly responsible for disappointments that she / he experiences surrounding the type of support that she / he receives from ACT.

Participants experience the relationship between themselves and their case manager primarily at the level of friendship, "In some ways I can open up more with [my case manager] than I can with [my friends]." *The element of friendship within the relationship with the case manger is viewed as extremely important by all participants.* In fact, friendship is perceived to be the critical ingredient that determines the strength and productivity of the relationship between client and case manager. Although this element of friendship was instrumental for all participants, this friendship took on added meaning for those participants who had fewer ties to the non-consumer community. For these participants, the friendship with their case manager represented their only relationship with a non-consumer/survivor: their only tie to something outside of the consumer/survivor world. In these instances, there existed a tendency to view the case manager as a more important figure in their life than in situations where participants had other connections to the non-consumer community.

Many of the participants seemed to be looking to the case manager to fill a void, to provide a close relationship akin to that of a best friend or confidant. In these instances, a transferred expectation is placed upon the case manager to provide an intimate friendship separate from the role of case manager. Possibly this expectation arises out of a non-verbal blurring of the lines between the role of client and case manager. The case manager, after all, does interact with the client within the context of a friendship. For example, the majority of interactions between the case manager and client, whether for the purposes of symptom assessment or goal identification, occur in the client's home over a cup of coffee. Possibly this blurring of the lines between the purpose of the interaction and the context within which the interaction occurs opens the door for unrealistic expectations on the part of the client. The participants who desire a close relationship with their case manger express a desire to have someone in their life who will take on a more therapeutic role, as one participant stated "find out [what makes] me tick":

> If [case managers] are really outgoing and giving you information about stuff you could be doing, or stuff that is offered and what is going on, or how you can get involved in stuff, well, then it is great, all that much better. But if they give you the impression they have 5000 people as a case load, and you just phone and they have three minutes to talk and the phone is ringing, so it is kind of superficial, I just think well…they don't have much time to get that involved in my life, or give me much help…

Interestingly, however, clients, in turn, do not express an interest in finding out what makes another person tick. This desire for a uni-lateral relationship is most likely precipitated by a life-long experience of relating to professionals in a therapeutic context. The confusion grows larger when this professional relationship is presented in the guise of a friendship. Although friendship is primarily experienced in the relationship with the case manager, *there also exists an element of separation between client and case manage*r. The underlying structure of the relationship surrounding the provision of support from the case manager to the client, facilitates a hierarchical division that places one individual in the role of expert and provider and the other in the role of learner and receiver. The professionalisation that is created by this division in role seems to underlie all aspects of the relationship with the case manager. This underlying role differentiation also seems to facilitate an experience of frustration and confusion for the individual in the role of client. If we consider that the relationship between client and case manager is viewed by the client primarily as a friendship, it is easy to see how professionalisation (a boundary that prevents the relationship from growing and expanding) would be met with confusion and frustration. Participants experience professionalisation as a sudden imposition of boundaries that occurs just when the relationship is beginning to become close.

Participants experience a perception of both the case manager and the psychiatrist as experts. These individuals are considered to possess a greater amount of knowledge than the client regarding what the client requires in terms of medication and support. Clients experience professionalisation as both a comfort and a frustration. On the one hand, professionalisation facilitates a deep trust in the ability of others to advise one's life. A comfort is found in the belief that one's life is in the hands of individuals who are "expert" in their estimation of what is best regarding medication and support.

> [The psychiatrist] decides how much [medication] there is, and I am happy with what he says, because he is the doctor not me... I trust him with my life... because he is older. He is old enough to be my grandpa and I trust the older people.

When one does not believe in the ability of professionals to determine what is best for one's life, however, professionalisation is experienced as a lack of choice. A significant sense of frustration and resentment occurs when one feels that decisions are being made about one's life by individuals who do not know what is best. It is at this point where professionalisation is experienced as a barrier rather than as a comfort: "I think they are hung up with their titles of professional, so that they are afraid to come out from behind it."

The relationship experienced between client and case manager within the context of support is characterised on various levels by tension. *This tension exists between the concurrent desires for dependency and autonomy.* On one level, participants experience the type of support that they receive from ACT as primarily focused on medication. All participants perceive medication as the primary purpose of ACT and the service that is provided to them on the most intensive basis. Whether participants' experience of this intensity as due to the concrete nature of this service as compared to services around psychosocial needs, is unclear. What is clear, however, is that participants consistently experience medication as the most intensive support provided by ACT. Participants who experience this intensive focus on medication as positive experience this type of service as a source of security.

> The best thing, I didn't know it at the time, but the best thing I needed was to go to the hospital and they planned it out and I did go to the hospital and everything worked out you know, so that was good.

Participants who experience this intensive focus on medication as negative feel as though medication is the only part of them in which ACT is interested: they have been reduced to a pill taker in the eyes of ACT. These individuals experience this view of themselves as a reflection of their own identity. They resent this narrow, view of themselves. It affects not only their own sense of identity but it also fuels a resentment over the localised nature of support that they receive from ACT. As one participant states:

> I feel that [ACT staff] are just figure heads, and they always come back to their list, like if you get talking about stuff and their like, the medicine, how is the medicine? You know and don't take a stand pretty much on anything...like they keep referring to the medicine three or four times during the space of a 20-30 minute talk...for them, everything resorts to a pill.

Most participants, particularly those who are not connected with supports outside of the consumer community, possess a strong desire to have support around needs that fall outside of medication and crisis support. These needs encompass what I would describe as higher order or meta needs. Meta needs are described by Maslow (Hall & Lindzey, 1985) as those needs that extend beyond the physiological, such as the need for socialisation, vocation, and integration:

> I think [ACT staff] are supposed to help people re-integrate into society right? Well, I don't think they do that at all, very much, so, and they don't say how can I help you find out where you can get more self-esteem, how can I help you find out where you can have more confidence so that when you do look to work, you will come across as confident enough to be considered a candidate, and stuff like that. How can I teach you how to be more assertive in relationships and not come across as aggressive

> when you get frustrated, so that people don't get scared of you and you don't get readmitted to hospital...

Although all participants experience an overwhelming need to pursue goals that addressed meta needs, participants who do not possess supports outside of the consumer / survivor community are more likely to look to ACT to provide them with this type of support. These participants have formed an expectation that ACT is responsible for ensuring that these needs are addressed. Possibly due to the slow nature of developing such psychosocial areas or due to a decreased focus in these areas on the part of ACT, participants experience significantly less satisfaction in these areas than they do in the areas of medication and crisis support. Participants who rely on ACT to provide support in these areas develop a resentment toward ACT for their decreased satisfaction in these areas.

Participants who do have some connection and support within the larger community also perceive ACT as placing an emphasis on medication and also feel a very strong need to formulate goals around meta needs. *These participants are more likely, however, to pursue these goals on their own and less likely to feel that this fulfilment of meta needs falls within the role of ACT.* These participants are more likely to feel that the main purpose of ACT is to provide support around basic physiological needs such as medication and crisis support, and are more likely to feel that keeping their involvement with ACT limited to this basic support is more beneficial to them in terms of community integration.

> [I] just [want to] have someone there to keep me on track...with a decent

> living…just by making certain I did things, like get my medications so I can go to work. I don't like the limitations of having someone looking after my affairs…I look after everything.

Interestingly, participants who seek support from ACT around meta needs are less likely than those who have outside support to turn the desire for the fulfilment of these needs into structured goals.

A general tension exists between wanting to place the responsibility for support on oneself and also wanting to place the responsibility for support on ACT. *Participants recognise that in order to move forward in their own recovery they need to move from dependency on ACT to a greater reliance on the self.* In this way participants experience a sense of frustration and resentment when they feel that the services provided to them by ACT are provided in a way that encourages dependency. At the same time as participants are experiencing this resentment of dependency, they are also experiencing a fear of becoming fully autonomous. By being completely independent of ACT, there is a fear that an invisible safety net will be removed.

> I am bored, but yet I am also afraid that if my life got too complicated, would I be able to handle it, you know. That's what I am afraid of you know. I sort of, you know, got too easy a life, but I don't want you know, life to be too hard, but I find life is way too easy right now.

This invisible safety net exists when there is a belief on the part of others that consumer / survivors cannot do for themselves or that they will need extra help. Certainly a resentment exists toward this attitude: it is unempowering, takes away opportunity and choice, as well as self-esteem. On the other hand, participants experience a sense of safety in this philosophy that is very powerful. This tension between the co-occurring desires for dependency and autonomy precipitates a confusion and a resentment that affects both the relationship between participants and ACT as well as the participants' own identity and ability to successfully pursue goals that fall outside of basic physiological needs.

The issue of needs and the type of services that participants desire from ACT is very complex. Participants experience ACT as a relationship of support that focuses primarily on issues related directly to psychiatric disorder (medication and crisis support).

> [ACT] just means that I get some help with problems that you run into being on your own after being in hospital...[my case manager] makes certain that I get my medication renewed, live half decently...[there is] somebody that will give you a helping hand to get things organised in your life.

All participants feel that support directed solely at this level of need is insufficient. *Each participant in this study experienced a propelling need to continue to reach beyond their present circumstances: to formulate goals that addressed areas of their life that extended beyond the physiological.* These goals represent in many ways a search for meaning, or to borrow a term from Malsow, a need to "self-actualise" (Hall & Lindzey, 1985). Participants speak of a desire for work, to be integrated with the community, to gain self-esteem, and to have more activity in their daily life. These strong desires exist despite of the existence of shelter, structured physiological support and standard income in each of their lives. In other words, although each participant's *basic* needs nave been sufficiently met (in terms of shelter, medication, food, clothing, stable income), there is a continued desire to address needs that go beyond the physiological.

Maslow, in his theory of needs, speaks at length about the human experience of developing varying needs that arise in a hierarchical fashion (Hall & Lindzey, 1985). Maslow has broken this set of needs down into five categories: physiological needs, safety needs (security, stability, structure, order), needs of belongingness and love (feel part of a home, family, circle of friends, working group), and esteem needs (strength, mastery, self-confidence, independence, respect of others, status, importance, dignity). These needs comprise the basic or deficiency needs. Meta needs and the need to self-actualise (aliveness, self-sufficiency, wholeness) comprise the growth needs. Maslow's theory contends that "the basic or deficiency needs are those that arise from some clear lack, or deficit, within the person. Once the deficiency needs are more or less satisfied, the meta needs, or growth needs, arise out of the human being's need to pursue goals, to continually go beyond, to become something better, rather than just to be, or to continue to exist" (Hall & Lindzey, 1985, p 65). The needs that participants are lacking and have now been met by ACT fit with the first two levels of basic needs as defined by Maslow. Physiological needs are addressed by medication and access to regular food. Safety needs are addressed by shelter, organisation and structure. Participants feel secure in the knowledge that there is someone they can count on in a crisis if something chaotic or unmanageable happens. The needs that participants don't feel have been satisfied are higher order needs and growth needs. Participants wish to formulate goals to pursue these needs because their basic needs have been gratified and they now seek to pursue goals that satisfy the next level of need. As Maslow explains "a new discontent and restlessness will ...develop unless the individual is doing what he individually is fitted for" (Hall & Lindzey, 1985 p.196).

Concurrent to the desire to self-actualise is the strong experience of feeling safe and secure physiologically. As each participant has been in a place at one time or another where their physiological needs were not met there is a strong reluctance to do anything that might jeopardise the current support that they receive around medication and crisis support:

> When [ACT] started giving me my pills...I didn't have to go to RMNE all the time because it was always closed when I went down there. The best idea was that I pick up my pills [at the ACT program] because I wouldn't have to worry about it...It was nice for them to fill [my dosset] because I wouldn't have to do it. Like I do it when I go down there, but it is like nothing, but if I had to do it by myself, I might slip up or something.

Is this desire to hold on to such intensive support around medication a result of learned helplessness: are participants' desires for such intensive medical support a symptom of a mental health system that has supported consumer dependency? Is it simply due to a lack of awareness on the part of participants: an inability to choose other alternatives because they have not been made aware of other options? Or is it due to the fact that intensive support around medication and crisis is an important element in the lives of individuals with psychiatric disorder? It is hard to tease out the intertwining effect of psychological, social and physiological elements that bear consideration when asking such questions. One thing that cannot be questioned, however, is the intensity with which each participant experiences the need for security in the areas of medication and crisis support. The concurrent need for both continued physiological support and the pursuit of self-actualised goals suggests the complex interconnection of physiological and meta needs for ACT clients.

The desire for work is strongly expressed by participants. *As the notion of work as noble permeates our whole culture it is the single most important symbol of community acceptance*:

> I will feel 100% integrated when I get a regular pay cheque. That is an integration, it is considered that your work merits a salary, and that is a big thing to feel, that you, someone feels your work merits a salary. That gives you a sort of a feeling of satisfaction.

> [I work] just to feel better about myself...Everybody needs a little self-esteem. You know, a reason for being alive, I did it for ten years, laying on my side eating chicken, drinking beer and watching T.V.

Participants' desires to pursue paid, independent work is very strong. Most participants, however, felt unsure about how to pursue this goal. They experienced a need for support in this area.

Choice comprises another interconnected level of the relationship between participants and ACT. For participants who have experienced institutionalisation in a psychiatric hospital, the choices that present themselves to clients of ACT are extremely important. Choices pertaining to such basic life decisions such as when one will wake, sleep, eat, watch television or go for a visit, are experienced as a freedom that hasn't always been present in their lives. This freedom represents a moving on from hospital or recovery. There is a sense of pride that they are in a position of having control over their daily lives.

> I think I have 100% choice to be with my boyfriend...and I have a choice to live here...I have a choice of what field of work I want to do, and I have a choice of hair colour, I have a choice of how to wear [my hair]. I can wear it whatever way I want. And I have a choice whether I want kids or not, and I have a choice of names...choice of what I want for supper. I have a choice of whether to smoke or not...[today] I decided to visit [a friend]...and I decided to go to the [day centre] and I decided to do the dishes.

All participants do express, however, some recognition of a lack of choice around more complex decisions that affect their lives. Choice within ACT is experienced as limiting. Decisions regarding the type of care that they receive from ACT are experienced as being in the domain of ACT staff and not within participants' control. Frustration is experienced regarding a perceived lack of choice around one's psychiatrist, how staff relate to them and how one spends their money. "I don't have any choice over their attitudes…you know I can't make them change their attitudes or make them re-examine their initial diagnosis, or say, maybe we should re-evaluate this person, you know I can't do anything about that:"

> When I really had not choice. I just sort of had to see this doctor and that was it…I wanted a choice. but they don't really have many psychiatrists, you know. So, I think they should have more psychiatrists there, you know, so they give more people choices.

> I wanted money. They didn't seem to want to give it to me. Well, like something I wanted. Usually, I do get it though, but not all the time, I don't get it as much as I like, because. like they are trying to make a savings account for me, eh. They are trying to save me money…I get discouraged, a little bit upset but there is nothing you can do about it, eh…I lied about trying to get some extra money, and it didn't work out, I got caught in my lie. they weren't pleased. they were mad at me. Ticked off at me, eh, because I was lying to them…they wouldn't give me the money.

Choice is also limited regarding options within the larger society. Many see their education and the amount of income as barriers toward choice around jobs and community integration.

> I don't have really good education and I don't really have a choice of too much jobs…it makes it impossible to have a choice if you know

> the amount of money I make and that.

There is a strong desire to expand outside of the relationship with ACT. *An important aspect of recovery for all participants is being able to cope in the "real world."* The consumer/survivor community is seen by all participants as a somewhat artificial world.

> You meet these people in these programs, and it is like an artificial world, and if things don't work out and as an easy way out, like getting divorced or something, they say, well, it wasn't me, it was the program…you know, it is just, so I back away from any of that.

Participants who do not have connections to the larger society view the consumer / survivor community as a safety net, a place where they can fail and not be rejected. These individuals do have a desire to be a part of the community but want to be able to have access to the consumer / survivor community if things are too hard. "You can be with people who have been through it like you, so you sort of feel like more family with them and you know that they are not going to be down on you if you blow your cool."

Participants who experience connections to the larger community, on the other hand, are more likely to reject the consumer/survivor community for fear of stigma from non-consumer / survivors. There exists a very strong sense that non-consumer / survivors would not be empathic or tolerant of their situation. To this extent, the possibility of anyone becoming knowledgeable about their psychiatric disorder is constantly perceived as a threat to the level of integration that they have achieved. Consequently, these participants feel that it is necessary to hide this part of themselves and in many ways end up rejecting the consumer / survivor community in order to decrease the probability that anyone in society will "find out."

> All of my friends are [non-consumer / survivors]. Cause, like my boyfriend doesn't want me to hang out with [consumer / survivors]. Because he doesn't want me to be classified, sort of labelled cause they, when you hang out with one person, you are painted the same colour as them. So all of my friends are outside, in the community.

Ironically, this tendency to hide a part of themselves leads to a feeling of isolation from the community that they are trying so hard to be a part of. In keeping a part of their lives hidden they feel as though no one truly knows them.

> I didn't want anyone at work to know that I'm a shrink patient...[but] if no one knows much about you, you are still within yourself and in an isolation situation...there is the odd sole that I can talk to, maybe four or five, different people that, you know, I can be honest with about myself.

The integrated experiences of participants presents an interweaving complexity of an existing sense of security and a desire for personal growth. In looking at the experiences of the participants as a whole we are presented with the intricacy that exists within the relationship that participants have with ACT. The intricacy of this relationship exists on many levels and can be seen in how participants conceptualise ACT, the relationship that exists between participants and case managers, the type of support that participants desire from ACT and the degree to which ACT is involved in the lives of the participants. Through their various interactions with ACT, participants experience confounding feelings of security, belongingness, isolation and diminished potential for growth. The result is confusion around the role of ACT and its place in their lives.

CHAPTER V

Positioning the Data within a Working Framework

In this chapter, I would like to position the findings of this study within a working framework. The purpose of employing an emergent design within a phenomenological study is to ensure that the meanings of individuals' experiences speak for themselves as much as possible. I felt that it was important to ensure that I did not look at the stories of the participants from the lens of a preconceived framework, as this framework may interfere with my ability to see the real essences and meanings in participants' stories. To this end, I purposely chose not to employ a preconceived framework from which I would view the stories shared with me by the participants prior to analysing the data. I preferred, instead, to try to fit a framework in post hoc fashion, to the themes and ideas that emerged from the data analysis. In taking this approach to framing the data, I feel more confident that the framework that I chose fits well with the experiences and themes presented by the participants.

The Life-Context Model

The essences and the meanings of the experience for the participants seem to fit best into an integrative framework that allows for the conceptualisation that a person is neither ill nor well at any given time. Rather, individuals are constantly in a state of coping with the concurrent potential for both illness and wellness.

The framework within which I have chosen to position the data is the life-context model proposed by Davidson and Strauss (1995). This approach is based upon the original work of George Engel who first discussed the biopsychosocial model in 1977.

The life-context model, as outlined by Davidson and Strauss (1995), is an approach that integrates both illness and health as ever-present states within the life cycle of an individual. Currently, two dominant approaches exist within the field of psychiatry for individuals with psychiatric disorders. One, the biomedical approach, places the illness as the central feature of the framework. Psychiatric illness is viewed similarly to a physical illness in that the approach is centred around the stabilisation and management of the illness. Davidson and Strauss (1995) point out the difficulty in encompassing the conceptualisation of the whole person when the focus of the approach is on the illness. A model that is based primarily on illness only encourages us to look at the person from the perspective of illness. On the other hand, the other dominant approach to working with individuals with psychiatric disorders, the empowerment model, is to focus on the wellness of the individual. The central focus of this approach is the life of the person within the context of wellness. A priority is placed upon working with the person around issues of quality of life, community integration, empowerment and hope. In order to focus on aspects of wellness, this model de-emphasises illness.

Davidson and Strauss (1995) suggest that the way in which these two approaches have presented themselves as mutually exclusive of each other has, in fact, created a situation in which the approach to working with individuals with psychiatric disorders is to slot individuals into categories of either illness or wellness. When you consider that psychiatric disorders are persistent across a life sphere, it becomes evident that the difficulty in choosing one or the other of these dominant approaches is that neither allows for a focus on both illness and wellness, which in turn does not allow for a focus on the whole person. In choosing either the biomedical approach or the rehabilitative approach, one is automatically choosing to de-emphasise a part of the whole person. Davidson and Strauss (1995) suggest that possibly these two apparently opposing models are in fact not incompatible but rather equally necessary in the way we conceptualise and work with individuals with psychiatric disorders. Davidson and Strauss (1995) refer to this situation as a state of antinomy where "...two approaches to the same issue are both required yet mutually exclusive; where, in other words, there are two contradictory perspectives, both of which appear necessary" (Davidson & Strauss, 1995, p.46).

Davidson and Strauss (1995) suggest that the next step in the progression of working with individuals with psychiatric disorders is to build on Engel's work to develop a "comprehensive model of psychiatric illness that integrates both disorder and person aspects" (Davidson & Strauss, 1995, p. 46). Engel put forth the notion of a "unified concept of health and disease that would bring together, in one model, both factors that focus on the person and those that focus on disorder" (Engel, p.105, as cited in Davidson & Strauss, 1995). Davidson and Strauss (1995) have expanded on this concept to include the conceptualisation of "a constant interweaving of [the biological, psychological and social] throughout the person's ongoing life, providing a context for the transformations of health, illness and recovery" (Davidson & Strauss p. 47). This life-context approach is presented as a unifying framework that has as its focus the person's life; recognising that the life sphere of any individual is comprised of "multiple dimensions of disorder, health and recovery" (Davidson & Strauss, 1995, p. 49). This focus involves "describing illness no longer as an absence or deviation, but in terms of its particular configuration of features and their impact on the person's life as a whole. It also entails describing aspects of a person's life only in terms of what it lacks" (Davidson & Strauss, 1995, p. 49).

The life-context model is in line with the community integration-empowerment approach described by Carling (1995) that emphasises viewing the individual on a holistic level; as a citizen of the community. The life-context model, however, places a larger emphasis on the interrelationship between illness and wellness. Davidson and Strauss (1995) outline four areas which they contend characterise the "concrete and ongoing life of the afflicted individual as the context for understanding and recovering from illness" (Davidson & Strauss, 1995, p. 50). These four areas encompass: (a) intentionality, (b) temporality, (c) meaning, and (d) the coexistence of competence and dysfunction.

Intentionality refers to the phenomenon that all individuals are propelled toward the continuous achievement of goals. Like Maslow's theory of needs, intentionality contends that once individuals have achieved goals that address a certain level of need, they continue on a constant pursuit of achieving goals that address larger and more complex needs. Intentionality is pre-set at all points in one's life sphere even at times when illness may be at the forefront of one's experience. Davidson and Strauss (1995) explain that "...one's projects may be interfered with in various ways, one's possibilities and choices may be restricted. Even in cases such as these, however, intentionality is never lost entirely" (p. 50).

Temporality refers to the fact that every given moment in one's life is temporal. Therefore, the state in which one exists at any given moment, whether that state is primarily one of illness or wellness, is also temporal. This temporal perspective is one that is not accommodated by any model that places a focus on either illness or wellness at the expense of the other. Davidson and Strauss (1995) explain:

> While attempts have been made to investigate psychiatric illness within a longitudinal framework. such attempts have most often either considered illness to be itself the product of faulty development or to have brought development to at least a temporary halt. In neither case is there an appreciation of illness as something that happens to people *while* they continue to develop, in whatever direction and at whatever pace. Shifting to a notion of development as not always following a strictly linear and normal path, and no longer seeing it as a naturally unfolding process in which individuals play only a passive role, may allow for a different appreciation of the interplay of development over time and the occurrence and effects of illness. (Davidson & Strauss, 1995, p. 51)

The third area, meaning, refers to the meaning that individuals attribute to the experiences in their lives. It is important that methods be utilised that provide us with the knowledge to understand the meaningful connections between biological, psychological and social events that make up one's experience of life. Davidson and Strauss (1995) stress the importance of...

> Providing the vehicle for the acts of sense-making essential to human

> consciousness, experiences both contribute to and are made up of the stories people compose about their lives. As such, they hold significance for individuals in ways that have not been captured adequately through quantitative approaches alone." (p. 57)

The last area of the life-context model is the recognition of the coexistence of competence and dysfunction. This area refers to the "simultaneous presence of strengths and weaknesses in any one person at any one time. Attention to the life of the person entails acknowledgement of both the illness (its signs and symptoms) and functional competence and coping" (Davidson & Strauss, 1995, p. 52). In other words, in order to fully account for a holistic approach that encompasses an individual's life context there must be acceptance of the simultaneous presence of both illness and wellness at any given time.

The Experiences of Participants as Grounded within the Life-Context Model

Meaning

One of the primary areas of the life-context model is related to the meaning of the subjective experience of a phenomenon. In conducting a phenomenological study on the experiences of clients of ACT, I was able to access the essences and the meanings of the experiences of five individuals. The phenomenological approach is suggested by Davidson and Strauss (1995) to be a methodology that "allows for an in depth study of people's lives as intentional, temporal and meaningful in nature" (p. 53).

Intentionality

Within the life-context model, intentionality refers to "the fact that a person is directed toward goals that are in a constant process of unfolding" (Husserl, 1983, as cited in Davidson & Strauss, 1995). The experiences of the participants encompass a strong desire to continue to pursue goals in their lives that meet needs beyond those that have been satisfied at the present. The experience is one in which individuals feel a sense of security and contentment around their basic physiological and safety needs. These needs have been addressed by access to medication, structured medication regimens and reliable continued support that can be accessed on an as needed basis. Frustration and despair exist, however, around the need to continue to pursue goals that meet higher order and meta needs. A desire exists to continue to pursue other goals such as those addressing issues of community integration, self-esteem, work, and daily activity. Participants experience frustration around how to pursue these goals. They feel they are somehow lacking in the knowledge and skills required to achieve these goals but the desire to have these needs met is very strong.

Temporality

Temporality, the third area outlined in the life-context model, refers to the issue of "the longitudinal nature of life…any given moment of a person's life is only a slice of the overall historical totality, merely one frame abstracted from a constantly running movie" (Davidson & Strauss, 1995, p.55). The participants experience a sense of temporality of their present state: there is an awareness that the goals and needs that they experience at one moment may be different in the next. Goals and needs that are currently focused around wellness may, in fact, be focused on illness at some point in the future. For this reason, participants experience a reluctance to fully detach themselves from access to support around needs that may be presently satisfied because there may be a need for those supports in the future.

Coexistence of Competence and Dysfunction

Participants experience a preference by others to place a focus on either their current state of illness or their state of wellness. Within ACT, they experience a focus on illness. The majority of conversations with the case manager and psychiatrist take place regarding medication or symptoms. In fact, the entire relationship with the psychiatrist is illness related. The supports that are often provided around issues of wellness (work, community integration, self-esteem) are often illness-focused. Focus is placed on what a person lacks in their ability to pursue a particular goal (i.e., sheltered workshops or supported approaches to work offer "support" to make up for skills they lack). Concurrently, participants experience the expectations of the community as focused on wellness. Participants feel as though there is no place for illness if they are to be accepted within the larger community. They feel that non-consumer / survivors would not accept that part of them. This creates a sense that only a part of them is welcome in the community, only a part of them can be expressed.

The overall experience is lonely and separating, participants feel that there is no where in which they are accepted as a whole person; there is no where that the co-existence of both illness and wellness are recognised and accepted.

CHAPTER VI

Outcomes and Implications

Consideration of the Limitations of the Study

With the choice of any methodological approach comes the limitations integrally associated with that particular methodology. The most obvious limitation associated with the phenomenological approach is the inability to generalise the personal experiences of a few individuals to a population. The experiences of the participants in this study are not only confined to the personal life situations of five people, but are also confined to the experiences of a single ACT team. The degree to which the experiences of the participants accurately reflect the experiences of other ACT clients both within CIP and within the greater ACT community is questionable. We can find some reassurance, however, in the fact that many of the findings are congruent with other findings in the literature. Findings in this study, for instance, point to a lack of satisfaction and fulfilment with regard to higher order needs such as vocation, education and community integration. Likewise, many quantitative studies have found few significant effects in the area of rehabilitation and social supports, suggesting a lack of focus in the provision of these types of services by ACT programs. Another major finding that came from this study was the perception of medication as the most intensive support provided by ACT. In conjunction with this finding randomised controlled trials of ACT have consistently produced findings of decreased hospitalisation and symptomatology also suggesting a treatment focus.

Limitations are also inherent in the sampling technique used for this study. Clients were selected simply upon their association with the CIP program and their availability for an interview. There are no assurances, therefore, that the individuals who participated in this study are representative of typical ACT clients in terms of age, gender, length of time in program, diagnosis or chronicity. In fact, it is probably safe to say that a majority of the participants in this study have been ACT clients longer (7 – 8 years) than the typical ACT client in Ontario (I base this assumption upon the fact that the oldest ACT team in Ontario was developed in Brockville only 10 years ago, Lafave, de Souza & Gerber, 1996).

Another important caveat to this study is the nature of the questions asked to obtain the experiences of the participants with ACT. The degree to which the data encompass the experience of individuals receiving ACT is dependent primarily on the ability of the questions to elicit the full meaning of the experience for the participants. In order to strengthen the integrity of the questions, I formulated an advisory group comprised of two consumer / survivors to help me devise the questions, the assumption being that, as a result of their shared experience of being consumer / survivors, the members of the advisory group would posses a personal knowledge of the types of questions that would enable ACT clients to express the meaning of their experience.

Lastly, as with any study performed in the human sciences, it is important to recognise that all individuals have experiences outside of the phenomenon that is being studied. We can never be sure to what extent the other experiences in one's life influence the way in which an individual interprets and experiences a particular phenomenon.

Future Studies

The findings of the subjective experiences of ACT for clients raise many questions for which more extensive investigations should be conducted. Primarily, investigations taking a more detailed look at the meaning of medication and the division of needs within the experience of ACT clients would serve to facilitate a larger discussion on the notion of developing a system that is based on the assumptions of intentionality, temporality and the co-existence of competence and dysfunction.

Outcomes in Terms of Social and Professional Implications

The experiences outlined in this study are particular to the unique experience of the five individuals who participated, as well as the unique structure of the Community Integration Program. The findings that have been formulated from these experiences then, are in no way generalisable across the experiences of all ACT clients. As such, these findings are not to be seen as a critique of the ACT model. Having said this, however, there are certain themes and patterns that come up across interviews that certainly lend themselves to a discussion of ACT.

The experiences of the participants in this study address the issues of intentionality, temporality and the coexistence of competence and dysfunction as presented in the life-context model (Davidson & Strauss, 1995). Participants experienced a lack of address of the dynamic nature of illness, the simultaneous presence of both wellness and illness and the ever present need for continuous achievement of personal goals. These findings have serious implications for the way in which the mental health field works with individuals with psychiatric disorder.

The experience of the participants in this study was that the services provided by ACT adequately met basic physiological and safety needs. Basic needs for individuals re-entering the community consist of an effective medication regimen, adequate shelter, nourishment and access to crisis support. Participants experienced a sense of safety and security from the knowledge that there was always someone to call in case of crisis. We cannot discount the importance of this experience for participants. For many, it was this sense of security around medication and crisis support that tied them to ACT despite other misgivings that they may have had about the program.

Unfortunately, however, designing a longitudinal model that places a primary focus on basic physiological and safety needs presupposes that individuals will not experience a continuous need to pursue goals that address larger and more complex needs. Although psychosocial factors which address higher order need areas such as vocation, education and socialisation are addressed within the services of ACT, participants consistently experienced these services as less intensive than those offered around medication and crisis. Participants also expressed a relative dissatisfaction with the degree to which they had achieved their goals in these areas. An argument could be made that the decrease in intensity experienced by participants around psychosocial services is due to the fact that services around medication and crisis often tend to be more concrete in nature than those that address psychosocial factors. Consequently, services related to medication and crisis support are perceived as being more intensive.

Ultimately, however, the argument as to why psychosocially-based services are experienced as less intensive is, in the end, less relevant than the fact of the experience itself. Consequently, despite the causal elements, the simple knowledge that participants experience low levels of satisfaction in the areas that address higher order, psychosocial needs is extremely valuable.

Is it necessary, however, that psychosocially based, higher-order needs be addressed by ACT? Is it possible that the very structure of ACT (one on one case management, assertive, in vivo) ensures that these higher order needs cannot be met by ACT? For instance, how do you develop community integration within a structure that is one on one and in vivo? How do you provide genuine friendship when the primary role is to provide services? How do you develop citizenship through an in vivo system?

When we speak of the need for community integration, friendship and citizenship, we are speaking of the need for community-building. Social services such as ACT, by nature, focus exclusively upon individual needs and in the process inadvertently decrease the level of recognition that these individuals hold many qualities that are very similar to other members of society. There is a need, both within the context of ACT and in the larger mental health system, for an approach that can accommodate the intentionality, temporality and the co-existence of competence and dysfunction that encompass psychiatric disorder. ACT is designed to target a specific portion of the psychiatric disorder population at a specific period in the course of the disorder. The nature of the ACT services are very intensive and ensure that the focus is both needs based and in vivo. This type of needs based, in vivo approach, although very successful in ensuring medication compliance and effective crisis management, also results in isolating individuals from the larger community. The pursuit of higher order needs such as vocation, personal esteem and community integration, is not achieved effectively in isolation of the larger community. ACT, like the mental health system, in general, attempts to address the needs of individuals with psychiatric disorders through specialised services. Needs around vocation, education and socialisation are addressed through programs designed specifically for individuals with psychiatric disorder. Hence, the aid that individuals receive from ACT and the mental health system is segregated from the larger community.

Building community for individuals with psychiatric disorder (whether clients of ACT or otherwise) may be one of the most important ways to provide individuals with the capacity to effectively pursue higher order and meta needs. The way to build community within the mental health system is to link individuals with psychiatric disorders with potential partners in the community (Kretzmann & McKnight, 1993). This is not to say, however, that there are no solid achievements that have been made by ACT. Certainly, extremely important issues have been effectively addressed by the intensive needs based approach with regard to the effectiveness of medication regimens and crisis management. Perhaps these issues are most effectively dealt with in this way. However, if we want to address the intentionality, temporality and co-occurrence of illness and wellness that exists in psychiatric disorder and if we want to address the life-context of individuals with psychiatric disorder, we need to build community capacity within the mental health system.

This is not to say that ACT should necessarily change its focus from an intensive, in vivo service to a builder of community capacity. My point merely being that a needs based, in vivo approach cannot adequately address needs that are based upon the desire for normalcy and integration. The type of approach that one would use to address physiological and safety needs is not necessarily an approach that is amenable to meeting higher order basic needs and growth needs. As each person lives her / his life within both the context of illness and wellness, individuals need to have access to both services that address the seriousness of psychiatric disorder and the equally important need to be a member of society. The need for access to both of these types of services is ever present even though the need for one over the other may be at the forefront at any given time.

Community building happens in the transaction we have with people: in the interdependence of individuals, families, community and society (Kretzmann & McKnight, 1993). In order to build capacity for individuals with psychiatric disorder we need to facilitate the opening of the door to community members, families, friends, to society. Consequently, we need to re-conceptualise what we provide to individuals with psychiatric disorders at both a program and a community level. It is vitally important that we not remove ourselves from the responsibility of addressing the higher order needs of individuals with psychiatric disorder: that we not place an emphasis on illness and only address issues of wellness peripherally.

Findings of this study suggest that we are not seeing the extent to which community integration is a struggle in the lives of individuals with severe psychiatric disorder.

These individuals have been integrated through an acknowledgement of difference and as such they exist on the periphery of society. As personal empowerment is interconnected on so many levels with community empowerment, it is impossible to empower any single individual without first addressing the disempowerment of the psychiatric community as a whole. In order to do this we need to develop resources devoted to building community capacity for individuals with psychiatric disorder. In keeping with the notion of temporality, we need to concentrate on forming an integrated, connected system that allows individuals to access services that meet their needs at a particular point in their life sphere. In order to accommodate this the mental health system needs to provide services based upon the recognition that the needs of individuals with psychiatric disorder will change in various ways as they continue to move through their lives and hence the need for access to services that address both illness and wellness is ever present. The lack of recognition on the part of the mental health system around the coexistence of competence and dysfunction can be seen in services such as the Family Benefits Allowance (FBA) system upon which many individuals with psychiatric disorder subside. Like many other services provided by the mental health system, the disability pension labels individuals with psychiatric disorder into either a state of illness or a state of wellness. If the person is in a state of illness and unable to work she / he receives FBA; if a person is well and able to work he / she is considered self-sustaining and no longer receives FBA. A system based upon the recognition of the co-existence of illness and wellness, however, would address the state of being well enough to want to fulfil the self-actualising need for productivity and worth through paid vocation and at the same time also accommodate the state of being too ill to be self-sufficient. Services such as ACT cannot be based upon an assumption that the primary need of individuals with psychiatric disorder will always be related to medication and crisis support and that the pursuit of higher order needs will always be secondary to basic physiological needs.

The need for access to intensive services around medication and crisis management may always be necessary in the lives of individuals with psychiatric disorder. Certainly, findings from this study would suggest that the services they receive from ACT in these areas are very important and in many cases is the expressed sole reason for remaining with the ACT program. The integral problem with the ACT model, however, is the presumption that if needs beyond the physiological are to be addressed ACT is somehow responsible for addressing them. I believe that ACT has tried to address these issues within the context of the existing model; however, an intensive needs-based, in vivo approach is in opposition to the type of support required to address needs based on normalcy, socialisation and integration. In the end, ACT has been unsuccessful in its attempt to address the higher order needs of individuals with severe psychiatric disorders. We need to re-conceptualise ACT as a component of the larger mental health system. Individuals need to have continual *access* to the type of intensive services provided by ACT regardless of the degree to which they *need* the service at any given time; an open door policy must be in place. However, individuals also need to be able to connect with the community in order to address higher order needs. There is need, therefore, for a system of capacity-building within the mental health system to build new relationships with resources that exist outside of the mental health community through concrete, mutually beneficial partnerships (Kretzmann & McKnight, 1993). It is important to note that I am not suggesting a step-down method. The step-down method that has been implemented by some ACT programs is a process of providing de-intensified services to ACT clients on a less frequent basis. Step-down methods, however, continue to be ACT in structure and it is this structure that is incompatible with producing citizenship, community integration. Building community capacity requires a more global address of the issues within a framework that will develop the opportunities for empowerment, community integration, for individuals with psychiatric disorder on a community wide basis.

In a phenomenological study, what is said is often as important as what is not said. It is interesting that some issues often associated with ACT, such as adequate housing (Mueser et al., 1998) and increased levels of cohersion (Nugent & Spindle, 1998) were not spoken of at great length by the participants. All of the participants in the study were comfortably sheltered in independent homes or apartments. I can only assume that the lack of emphasis on housing within the stories of the participants is a reflection of the client's satisfaction with this aspect of their lives. The issue of cohersion, on the other hand, is more complex. Issues related to control were certainly evident in participant's stories of their experience with ACT. Frustration was expressed at choice and control that was lost at both the level of ACT and the greater mental health system. This frustration over choice and control, however, did not translate into a view of the client – case manager relationship as cohersive. My own explanation for this would be that participants are reluctant to see the case manager in a negative light as this would threaten the link to support that currently exists through the case manager. This explanation may also account for the significantly more negative view of ACT often presented by consumer / survivors who are not currently clients of ACT.

In summary, the knowledge and understanding of the experiences of ACT clients provided by this study, hold important social and professional implications for both ACT and the larger mental health system. Knowledge of individuals' experiences of the ACT model bring to the forefront the need to look at issues regarding individuals with psychiatric disorders from a new perspective, one that is rooted in the recognition of the full life context of the individual.

Final Reflection

Since the first attempts at deinstitutionalisation in the 1950's, the mental health community has struggled to integrate individuals with psychiatric disorder into the community. With each new piece of knowledge and understanding we grow in our capacity to provide the resources for true integration. The stages of growing have seen us through the initial conceptualisation of placing individuals with psychiatric disorders into the community, the recognition of the need for continuous access to support around medication and crisis management and most recently, the need for support around the pursuit of higher order needs. To progress in our journey toward true integration we again need to reconceptualise the way in which we perceive and work with individuals with psychiatric disorders. Citizenship will only be achieved if there is recognition on a systemic level of the interrelationship of wellness and illness. Individuals need to be able to move easily through a system that does not require a person to be either ill or well but that is prepared to equally address needs that fall into either category.

For many participants, ACT provided a service that enabled them to maintain a structured medication regimen which often meant fewer relapses into severe illness as well as fewer and shorter returns to hospital. This type of support was considered extremely important by most participants. But, community integration does not end with maintaining people in the community and the responsibility of the mental health system does not end with the provision of services around physiological needs. Recovery for individuals with psychiatric disorder should include being a part of society, through socialisation, work, education and self-sufficiency. Only a recognition of the complex interconnectedness of illness and wellness and the need to rely on a variety of different supports will enable us to meet this responsibility.

In conclusion, I would like to put forth a list of recommendations based upon my own learning from conducting this study. These recommendations are intended for individuals involved in the planning, development and implementation of ACT services. First, it is extremely important that a priority be placed upon the clarification of the role the case manager plays in the lives of ACT clients. Clarification needs to occur around issues of power imbalance. Clients need to know the degree to which the relationship with their case manager is personal and to what degree it is professional. Clients need clarification around these issues so as to avoid the frustration and confusion that arises from the lack of articulation that currently exists in these areas.

It is also important for policy and decision-makers as well as ACT providers to recognise and understand the localised way in which clients conceptualise ACT. In viewing ACT primarily as a relationship between themselves and their case manager, ACT clients are not prepared to relate to ACT in the manner of true consumer. Unless clients have an integral awareness of the broader organisational structure of ACT they are not in a position that would enable them to choose, critique or influence services.

We need to address the rather persistent effects that a long term relationship with the mental health system has upon the socialisation of individuals with psychiatric disorder. The effects of constantly being involved in psychotherapeutic relationships with professionals provides clients with artificial representations of relationships and creates unrealistic notions of relationships on the part of the clients. This constant exposure to therapeutic relationships facilitates a view of all relationships as unilateral. Unfortunately, when clients then go outside of the mental health community to elicit relationships they lack the experience and knowledge around how to be reciprocal in a relationship.

We need to recognise the value of paid work as distinct and separate from volunteer or under paid work. Adequate payment (at least minimum wage) for work is seen as a comment on the value that society places upon both the work and the person who provides it. In other words, feeling as though one's work is valued by the community is synonymous to feeling accepted by the community. The biggest leaps toward full community integration for individuals with psychiatric disorders will come from opportunities for paid work in the community. Although adequately paid work within the consumer / survivor movement exists and is rewarding, more effort needs to be placed on the development of independent opportunities in the community for individuals with psychiatric disorder.

The lack of satisfaction experienced around personal growth presents an issue that questions the ability of ACT, as it is currently structured, to adequately address the clients' needs to pursue self-actualisation. At its basis there needs to be a recognition within the mental health system of the need for self-actualisation in all human beings. A recognition solely of individual physiological needs neglects a recognition of the extensive range of needs that comprises the whole person. It also needs to be recognised, however, that mental health organisations cannot *provide* services to meet these needs. Personal growth needs, by their very nature, can only be attained through the individual. The mental health system, however, does hold the potential, and I believe the responsibility, to impact the facilitation of opportunities for personal growth for individuals with psychiatric disorder through community development.

In order to adequately address the needs of individuals with psychiatric disorder we need to begin to look beyond individual clients and mental health organisations in order to incorporate the efforts of the community. Interventions that address the actions, behaviours, beliefs and values of the community need to occur if we are to achieve true community integration for individuals with psychiatric disorders. A reciprocal relationship needs to exist between the mental health system, the consumer / survivor community and society at large in order to create the type of environment that will enable individuals with psychiatric disorders to live full and complete lives as citizens of our communities.

We need to implement continuous dialogue around the values upon which ACT is structured. As we continue to grow in our conceptualisation of how we view and work with individuals with psychiatric disorder the values that guide us in our work also continue to emerge. It is important that we ensure that the services we have in place also continue to reflect our emerging value base. A continuous, open discussion about our values is necessary if we are to ensure that the services we provide adequately represent these emerging values.

In order to truly achieve community integration and empowerment for individuals with psychiatric disorder, however, we must go beyond the discussion of values to examine the structure that exists both within ACT and within the larger mental health system. It is true that the current structure of ACT is based upon a set of values that place a focus on illness. It is this emphasis on illness and peripheral treatment of wellness that inherently creates barriers in the way of empowerment. If we wish to affect the success of ACT in addressing issues of wellness for individuals with psychiatric disorder, we need to re-evaluate the structure of ACT as well as the values upon which this structure is based. To say, however, that the structure of ACT should be based upon the values of wellness would fail to recognise the seriousness that psychiatric disorder can play in the lives of individuals. Just as a systemic structure based on illness does not adequately address states of wellness experienced by individuals with psychiatric disorder I believe that structures based on wellness would equally fail to adequately address severe experiences of illness. The systemic structure of ACT provides us with the key to how we will grow in our relationship with individuals with psychiatric disorder. This structure needs to be reconceptualised in a way that acknowledges first and foremost the intricate complexity of the co-existence of illness and wellness. We need to recognise that a person does not experience one state over and above the other. As a result, individuals do not benefit from services that place an emphasis on one state or the other. Instead, structures need to be built upon the assumption that individuals with psychiatric disorder will experience *both* periods of wellness and periods of illness. We need to build a system of mental health care that is designed to accommodate this notion of temporality. The systems that we design also need to reflect the notion that *all* individuals experience an innate need to self-actualise: to grow beyond themselves. In this regard, simply providing services around individuals' most basic physiological needs is not enough.

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Appendix A

Queen's Ethics for "Variations in Assertive Community Treatment: A study of approaches and outcomes of four teams in South Eastern Ontario" research project.

1. RATIONALE:

a. Background:

This research project has received funding through the Community Mental Health Evaluation Initiative. A consortium of provincial mental health organizations combined their resources to improve through research and policy development, the delivery of mental health care services and supports in Ontario. The Ontario Mental Health Foundation, The Canadian Mental Health Association – Ontario Division and the Health Systems Research Unit of the Clarke Institute of Psychiatry formed a Mental Health Policy Research Group to research and advocate solutions for major issues and problems in the mental health arena. The Community Mental Health Evaluation Initiative was one component of the Group's mandate. This submitted research project has been granted funding, along with six other research projects, through a competitive, peer review process, to study various aspects of mental health reform in Ontario.

A Multi-site Coordinating Centre has been established with the primary goal of collecting and analyzing a common protocol of data across the project sites. In this manner each of the funded research projects will address research questions common across the sites, and research questions specific to the project. It is hoped that information collected from across sites will provide important insights into the progress of mental health reform across Ontario. The Multi-site Coordinating Centre includes investigators from the Health Systems Research Unit at the Clarke Institute of Psychiatry and the principle investigators from the 6 projects in the province awarded funding through the Community Mental Health Evaluation Initiative.

b. Rationale for this research study

A major focus of mental health reform in Ontario is the development of case management services that facilitate the community adjustment of adults with serious mental illness. The program for Assertive Community Treatment (ACT), as developed in Madison Wisconsin by Test, Stein and colleagues, uses an intensive and continuous treatment model to support adults with serious mental illness in the community. Empirical studies of ACT have been favourable. The model has been widely replicated in the United States and abroad and it was recently endorsed by the Ontario Ministry of Health as a service model of choice for people with serious mental illness. Many local planning initiatives have recently focused their attention on the potential for ACT teams. Sound evaluation studies are essential to determine the effectiveness of these teams in helping individuals with severe psychiatric disorders to live successfully in the community in a cost effective manner.

Within the field of community mental health, Kingston and Brockville are unique in that they have four community based teams developed according to the ACT model. This research study will evaluate the effectiveness of these four teams in meeting the objectives of mental health reform. Specifically the study will evaluate:

1. Whether the individuals with severe psychiatric disorders serviced by these teams demonstrate: improved community tenure; improvements in psychiatric impairments and symptoms; improved community adjustment and quality of life; increased sense of empowerment and; satisfaction with services.
2. The costs associated with ACT services.

Although the essential elements of an ACT team have been identified, the relationship between specific features of the team and outcomes is unclear. Despite considerable attention to the refinement of the critical dimensions of ACT, replications of the model have been subject to adaptations. The impact of modifications to the model has been virtually unexplored. Determining the impact of innovations to the ACT model is essential to the development of best practices in community mental health.

The four teams included in this study have been developed according to the ACT model. Closer examination of the teams indicates that each team has made adaptations and refinements to the original ACT model. By identifying and examining the relationship between these adaptations and specific outcomes this research study will help us to understand the following:

1. Are there characteristics of the model that can be adapted without sacrificing positive outcomes? Adaptation of the model may serve to contain the costs associated with the service.
2. Despite an operational definition of "serious mental illness" this is a heterogeneous group of people with respect to diagnosis, treatment history, socio-economic status and other characteristics. Is it possible that critical features of the ACT model will vary with specific client features. This information would assist with the development of these services, ensuring a closer fit between program features and actual client need.
3. It may be that modifications to ACT are able to maintain the positive outcomes which have been associated with the model and improve on the outcomes associated with community life and social adjustment.

2. RESEARCH PLAN

a) Subjects:

Subjects from four Assertive Community Treatment (ACT) teams based in Kingston and Brockville, Ontario will participate in this study. As a component of the ACT team guidelines, all participants will reside and receive services in the community. The nature of the data to be collected and the data analysis techniques that will be used require a large sample. The investigators are aware, however, that the costs associated with studying all clients across the four teams is prohibitive. As well the likelihood of all clients participating in the study is slim. Therefore, investigators decided that it would be appropriate to aim to include 50% of the clients for each team. The subjects that will participate in this study will be randomly selected.

b) Method:

As demographic data are readily available this information will be collected on 100% of the clients in each ACT team (see Appendix A under Status Measures). Fifty percent of the clients in each team will be randomly selected to participate in a series of interviews that will occur at baseline, during the ninth and eighteenth month. Each period of data collection will occur within a three week time frame. The interviews will be conducted by three trained research interviewers. A pilot study indicates that the series of interviews should require approximately one hour of a subject's time per annum. New clients entering the ACT teams will also be randomly selected to participate in the study. As it would not be possible to include a true control group for this study, new clients to the programs will serve as a semi-control group.

c) Analysis:

Each subject will be interviewed using a pre-determined set of interview scales that have been selected based upon a) their previous use with individuals with mental illness and b) their strong psychometric properties. Some scales will be common across sites and others will be specific to this study (see Appendix A for a list of these scales). Data from these interviews will be analyzed using univariate and multivariate techniques. The outcome data will be analyzed in terms of treatment variables such as length of hospitalization, severity of illness, symptomology; psychosocial variables such as quality of life, social networks, socio-environmental status, community integration; program variables such as nature of services offered and client satisfaction with service; and cost variables. A list of the various hypotheses for this study are included in Appendix C.

3. SAMPLE

The Brockville Assertive Community Rehabilitation Program team currently serves 80 clients. Forty (50%) clients from this program will be recruited to participate in this study. Participation in this study will constitute participating in a series of interviews given by research interviewers at baseline, during the ninth and eighteenth month. Interviews will take place over a three week period and will require the equivalent of one hour of a subject's time per year.

4. RISKS OF PARTICIPATION AND BENEFITS TO SUBJECTS

RISKS

Clients participating in this study may experience some feelings of discomfort as a result of unfamiliarity with the interviewer and the interview questions. This period of discomfort is most likely to occur early in the interview phase and will subside when the client becomes more familiar with the interview structure and with the interviewer. Similar research projects in the past have successfully employed similar methodologies and interview scales. The investigators believe, therefore, that the protocol proposed here will not create undue risk for clients.

The interviewers associated with this research project will be trained in the use of interviewing skills and will also devote time to developing a rapport with study participants. Interviewers will refer any study participant who appears to be in distress to the service providers. Study participants will be informed that they can end the interview sessions, modify the length of the interviews, and arrange a flexible interview schedule to meet their personal needs.

4. BENEFITS

There will be direct benefit for study participants in the form of an honorarium of ten dollars per subject and will be given to clients for the purpose of recognition of participation in the study. This small sum is not significant enough to be considered as an incentive or coercive act. An indirect benefit for study participants will be the potential to improve the services offered by the four programs. Study participants may experience a psychological benefit from having the opportunity to talk to someone about their life situation. They may experience a sense of altruism in participating in a study that may be of benefit to other people with serious mental illness.

5. ALTERNATIVES AND/OR STANDARD THERAPY

This study does not provide any therapy to participants, nor is any therapy withheld from them.

6. DATA MONITORING

Monitoring will be performed by one of the investigators (GJG). Participants are free to withdraw from the study at any time

7. CONSENT AND COERCION

Each potential study participant will be approached by a staff member of the ACT team. The staff member will use a script (Appendix B) to provide the client with a description of the study. If the client wants to learn more about the study, he/she will complete the form at the bottom of the script to indicate interest in meeting an investigator or researcher, and the preferred method of contact. A research assistant of the study will then contact the client to arrange a meeting. At this meeting, a description of the study will be provided, an if the client is interested they will be asked to provide informed consent (see attached consent form). Since these study participants will all be living in the community and managing their own affairs they are considered capable of providing informed consent. Informed consent will be repeated at the nine month and eighteen month data collection periods.

Study participants will be reimbursed for travel expense incurred and will be compensated $10.00 annually for participation in outcome interviews. This compensation is consistent with the policies of the funding organisation. Consumers of mental health services in Ontario have spoken out against traditional research practices that have failed to financially recognise the active role they play in mental health evaluation and research. The amount has been selected to acknowledge the time and effort and costs associated with participation in the study, but not instil a sense of coercion

8. CONFIDENTIALITY:

The interviews will be held in locations which ensure privacy. Although staff of the four services will know which clients are involved in the study, data will be collected to ensure confidentiality. All data will be identified by code. The names of participants associated with these codes will be held only by the principal investigators. Names, addresses and other identifying information will be stored separately from the data. Information in related reports and publications will focus on data collected for the group and will eliminate any information which may identify an individual study participant. All subject information and data will be stored in locked filing cabinets in locked offices. The interview and questionnaire data will be kept for five years following the completion of this study and after this only computer records will be maintained. Paper records will be shredded.

The following issues related to confidentiality and the sharing of information with the Multi-site centre have been addressed:

1. All identifying information will be stripped from the data records before they are transferred to the common data set
2. The consent form has been modified (see attached) to inform prospective participants of the additional use of the study data.
3. A copy of the final protocol, outlining the common instruments to be used across the sites, and those specific to this project, has been attached.
4. A policy and protocol regarding ownership of and access to the common data set will be developed by the Coordination Centre investigators.
5. The multi-site study will undergo its own separate scientific and ethical review at the University of Toronto.

9. PATIENT RECRUITMENT

A roster of the total client population for all four programs will be obtained from program managers. Descriptive data for this group will be obtained directly from hospital and program records. The roster will be used to select a random sample of 50% of the patients who will be recruited to participate in the collection of outcome data at baseline, 9 month and 18 month intervals. A staff member will approach each randomly selected patient to provide general information about the study and to inquire about the client's willingness to meet with the study researcher. Procedures as outlined in number 7, Consent and Coercion, will be followed.

Over the first two years of the study, all new clients in each program will be approached and invited to participate in the study. The same recruitment procedures, as described above, will be followed.

10. BRIEF DESCRIPTION OF PROJECT

A major focus of mental health reform in Ontario is the development of community based case management services for persons with serious mental illness. Assertive Community Treatment (ACT) has been shown to be an effective model of case management for maintaining community tenure for persons with serious mental illness. Four ACT model teams located in Brockville and Kingston will be study to evaluate their effectiveness in meeting the goals of mental health reform in Ontario. In addition, while the essential elements of the ACT model have been identified, the relationship between specific features of the team and client outcomes in unclear. This study will identify the adaptations and refinements from the standard ACT model for each of these four teams and examine the relationship between these variations and specific client and service outcomes.

This three year prospective study uses a quasi-experimental design. Data on demographics, hospitalizations and symptom severity will be collected from all clients (n=350) of the four services. A random sample of one half of the total client population will be recruited to collect data on outcome measures (n=175). Also data will be collected on all new referrals and analysed separately (n=120). Measures for fidelity to the critical dimensions of the standard ACT team will be completed for each of the four teams. Team activity measures will be completed over a two week period at baseline and at nine month and eighteen month intervals. Outcome variables include severity of illness, socio -environmental status, empowerment, client satisfaction, social networks, quality of life, community integration, and cost per client. Client outcome for the randomly selected sample will be collected annually by trained research assistants. Data will be analysed using univariate and multivariate statistical techniques.

QUEEN'S UNIVERSITY HEALTH SCIENCES & AFFILIATED TEACHING HOSPITALS RESEARCH ETHICS BOARD REVIEW APPROVAL

Queen's University, in accordance with the "Guidelines on Research Involving Human Subjects. 1987," prepared by the Medical Research Council, requires that research projects involving human subjects be reviewed annually to determine their acceptability on ethical grounds.

A Research Ethics Board composed of:

Dr. A.F. Clark	Head and Professor, Department of Biochemistry, Professor, Department of Pathology, Faculty of Health Sciences, Queen's University (Chair)
Dr. B. Appleby	Departmental Assistant, Bioethics, Kingston General Hospital Instructor, Department of Family Medicine, Queen's University
Dr. N.J. Delva	Associate Professor, Department of Psychiatry, Queen's University
Dr. S. Irving	Psychologist, St. Mary's of the Lake Hospital
Dr. K. James	Associate Director, National Cancer Institute of Canada Clinical Trials, Queen's University Associate Professor, Community Health & Epidemiology
Professor E. Kauffman	Assistant Professor, School of Nursing, Queen's University
Dr. J. Low	Professor, Department of Obstetrics and Gynaecology, Queen's University and Kingston General Hospital
Ms. F. O'Heare	Director, Risk Management Services, Kingston General Hospital Assistant Professor (Adjunct) School of Nursing, Queen's University
Dr. J. Parlow	Associate Professor, Department of Anaesthesia Assistant Professor, Department of Pharmacology & Toxicology, Queen's University
Dr. W. Racz	Professor, Department of Pharmacology & Toxicology, Queen's University
Dr. J. Rapin	Assistant Professor, Department of Emergency Medicine, Queen's University
Dr. M. Schumaker	Professor, Department of Religious Studies, Queen's University
Dr. S.J. Taylor	Bioethicist, Faculty of Health Sciences, Queen's University and Kingston General Hospital; Assistant Professor, Department of Family Medicine, Queen's University
Dr. G. Torrible	Community Member

has examined the protocol and revised consent form for the project entitled "Variations on Assertive Community Treatment: A study of approaches and client outcome of four teams in South Eastern Ontario" as proposed by Dr. S. Eastabrook of the School of Nursing and Professor T. Krupa of the School of Rehabilitation Therapy at Queen's University and considers it to be ethically acceptable. This approval is valid for one year. If there are any amendments or changes to the protocol affecting the subjects in this study, it is the responsibility of the principal investigator to notify the Research Ethics Board. Any adverse events must be reported to the Chair within 48 hours.

Albert Clark
Chair, Research Ethics Board

June 26/98
Date

ORIGINAL TO INVESTIGATOR - COPY TO DEPARTMENT HEAD - COPY TO HOSPITAL(S) - P&T - FILE COPY

NURS-073-97
97-12-08

Appendix B

Letter of Intent

Salinda Horgan
Queen's University
Kingston, Ontario, K7L 3N6

February, 1999

Participant Address

Dear:

I am the Project Coordinator of the "Variations in Assertive Community Treatment; A study of approaches and client outcomes in South Eastern Ontario." I received your name because you agreed to participate in this study in September 1998. I would like to inform you of a smaller research study I am conducting with clients of the Community Integration Program which is part of the "Variations in Assertive Community Treatment: A study of approaches and client outcomes in South Eastern Ontario" and is also the basis of my thesis for Wilfrid Laurier Univeristy. The main question that this research will address is: *What is your experience of Assertive Community Treatment?* As you are currently receiving services from the Community Integration Program I would like to ask you to participate in this study.

Participation would involve a 45 minute personal interview that would be conducted at your choice of either your home or in an interview room at the Community integration Program or Queen's University. The interview would be taped and would consist of questions regarding the meaning and importance which you place upon holistic services. The questions in the interview will address areas that relate to:

1) The value that you put on the CIP program.
2) What the CIP program means to you.
3) The types of relationships that you have in your life.
4) Your personal goals.
5) How integrated you feel in the community.
5) The experiences that you have had in the CIP program.

The interview will be transcribed and a copy of the transcription will be sent to you so that you can make suggestions for changes prior to the analysis of the data. The information that you provide will be kept confidential and in no way will the final report identify you as a participant. Approximately 10 clients from the Community Integration Program will be interviewed for this study. You will receive a copy of the final report once the study has been completed.

It is your decision if you want to take part in this study. You can change your mind and leave the interview at any time. This will in no way affect the services you receive from the Community Integration Program. You will still receive the best care they can provide. If at any point you decide that you do not wish to complete the interview the tape will be erased and nothing that you have said will be used as data for this project.

If , at any time, you have any questions about this study you can call me, Salinda Horgan at 533-6000 ext. 74756 or my thesis supervisor, Steve Chris at (905) 994-0198. If you have any questions about your participation or rights in this research, pplease contact Dr. Linda Parker who is chair of the Research Ethics Board at Wilfrid laurier University (705)884-1970 ext. 3126)

Sincerely,

Salinda Horgan, M. A. Candidate

Appendix C

Consent Form

Wilfrid Laurier University
Informed Consent

The Lived Experience of Receiving Assertive Community Treatment; A Phenomenological Study

Details of the study

My name is Salinda Horgan and I am the Project Coordinator for the "Variations in Assertive Community Treatment; A study of approaches and client outcomes of four teams in South Eastern Ontario." I received your name because you agreed to participate in this study in September 1998. I am working on a smaller research study which is part of the "Variations in Assertive Community Treatment: A study of approaches and client outcomes in South Eastern Ontario" project and is also the forms the basis for my thesis work at Wilfrid Laurier University. The title of this study is "The Lived Experience of Receiving Assertive Community Treatment; A Phenomenological Study."

The purpose of this research study is to help us understand how services such as the Community Integration Program may or may not be helpful to people who have had long term mental health problems.

I am asking you to take part in this study because you are in the Community Integration Program.

What's Involved?

The researcher will conduct a personal interview with you. This interview will concern your experience as a client of an Assertive Community Treatment Team. The interview will be taped. Only myself and the person who transcribes the interview will hear the tape. The tape will be erased as soon as the interview has been transcribed. It is expected that the interview can be completed in one visit for a total time of 45 minutes. A break will be built into the interviews, but you can have additional breaks if you feel that you need them.

Participation in this study should not cost you anything. You will be given the money to cover any travel costs that you may have as a result of participating.

You will be paid ten dollars for participating in the interview. This is a small amount of money to recognise the time and effort you put in to help complete the study.

Risks

No risks are expected from taking part in this study. The interview will be taped and this may make you feel nervous during the interview. If you feel uncomfortable during the interview please let the researcher know. You can take a break, or meet at another time. You can decide to end your participation in the study. If there is any question you do not wish to answer, just tell the researcher to skip it.

Benefits

You may not benefit directly from this study. A possible benefit for you is the chance to talk to someone about things that are important to you.

Confidentiality

Any information that you give for this study is confidential. Your case managers and the other staff of the Community Integration Program will not be informed about the information that you give me. Instead of your name, a code number will be used to identify the information you provide. The information will be kept in a locked storage space at Queen's University in the School of Nursing and will be destroyed after 7 years. Any research reports that come from this study will not identify you in any way. The reports will be written about everyone that takes part in the study, as a group. As this research is part of the "Variations in Assertive Community Treatment: A study of approach and client outcomes of four teams in South Eastern Ontario" study the principle investigators for that study; Ms. Terry Krupa an Assistant Professor in the school of Rehabilitation Therapy at Queen's University and Dr. Shirley Eastabrook an Assistant Professor in the School of Nursing at Queen's University, will also have access to the data.

Voluntary Participation

It is your decision if you want to take part in this study. You can change your mind and leave the interview at any time. This will in no way affect the services you receive from the Community Integration Program. You will still receive the best care they can provide. If at any point you decide that you do not wish to complete the interview the tape will be erased and nothing that you have said will be used as data for this project.

Feedback

You will receive a copy of the transcribed interview one or two weeks after the completion of the interview so that you can review it and provide me with suggestions for adjustments prior to data analysis. You will also receive a more in depth report of the background of the research, how the information was gathered and what the findings were. I anticipate completing this report by January 2000.

Participation Statement

I, ___________________(print name of participant) have read and understand what is involved in the study. My questions have all been answered. I have had enough time to think about whether I want to take part. I am signing this form voluntarily (on my own). I know that I can change my mind and not take part at any time. I will still receive the best care available. If I have more questions I will call: Salinda Horgan at 533-6000 ext. 74756 (researcher); Dr. Steve Chris at (905) 994-0198 (thesis advisor); Dr. Shirley Eastabrook at 533-6000 ext. 74755 (principle investigator); Professor Terry Krupa at 533-6236 (principle investigator). If I have questions about my participation or rights in this research, I can contact Dr. Linda Parker who is chair of the Research Ethics Board at Wilfrid Laurier University (884-1970 ext. 3126).

______________________ ______________________

Signature of Participant Date

______________________ ______________________

Signature of Investigator Date

APPENDIX D

INTERVIEW GUIDE

Interview Guide

A) Value of ACT

- → What does CIP mean to you?
- → What kinds of things do you do in your week?
- → Is there anything major that is coming up for you this week?
- → What things do you look forward to in your week?

B) Concept of ACT

- → What does CIP do?
- → What activities have you participated in?
- → What is the most important thing that CIP is helping you with now?

C) Relationships

- → What qualities are important for a case manager to have?
- → What do you value in your relationship with your case manager?
- → Scenario: Your case manager changed jobs and went to work with another team. If you had the choice would you go with your case manager or stay with CIP?
- → Do you wish that you had the kind of relationship that you have with your case manager with someone in the community?

- → What kinds of things do you do with your friends?
- → What do you like to do with your friends?
- → How many of your friends are from the psychiatric community?

D) Personal Goals

- → Where do you see yourself in five years in terms of employment?
- → " " education?
- → " " family relations?
- → " " social relationships?
- → " " housing?
- → " " income?

E) Community Integration

- → Would you like to spend more time with people who don't know that you have a psychiatric illness?
- → Scenario: Say you knew a person who was a client of CIP and they were a really good baseball player. What if she/he had a choice of two teams to play on, one was a CIP baseball team that was made up of staff and CIP clients or a community baseball team. Both teams have good and bad points about them. If the person joined the CIP baseball team they would already know everyone. On the community team the person would be able to meet new people who didn't know

that they had a psychiatric illness. Which team do you think the person should join?

- → How many conversations did you have yesterday?
  who were they with?

F) Choice

- → This week when you saw your case manager did she/he suggest things for you to work on or do this week?
- → Does your case manager often suggest things for you to work on / do with your time?
- → When you discuss things that you can work o or do with your time do you also have your own suggestions?
- → Are there times when you disagress with your case manager about how you should be spending your time?
- → What happens when you disagree with your case manager about how you should be spending your time?
- → Did you make any decisions or choices today?
  What were they?

G) ACT Experience

- → Tell me about your best experience with CIP
- → Tell me about your worst experience with CIP
- → Are there areas in which CIP could be better?
  What are they?

APPENDIX E

WILFRID LAURIER UNIVERISITY ETHICS APPROVAL

Wilfrid Laurier
University

Founded 1911

August 6, 1999

Ms. Salinda Horgan
Department of Psychology
Wilfrid Laurier University

Dear Ms. Horgan:

Re: Your Research Proposal Entitled, "The Lived Experience of Receiving Assertive Community Treatment; A Phenomenological Study"

I have reviewed the changes to the above proposal and determined that they are ethically sound.

If the research plan and methods should change in a way that may bring into question the project's adherence to acceptable ethical norms, please contact me as soon as possible and before the changes are put into place.

Yours sincerely,

Linda Parker, PhD
Assistant Dean of Graduate Studies and Research, and
Chairperson, WLU Research Ethics Committee

LP/jb

The Dean of Graduate Studies and Research
Wilfrid Laurier University, Waterloo, Ontario, Canada N2L 3C5 (519) 884-1970 Fax: (519) 884-1020