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Facilitating Social Integration for People with Severe Mental Illness

Sheila Linz

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FACILITATING SOCIAL INTEGRATION FOR PEOPLE WITH SEVERE
MENTAL ILLNESS

BY

SHEILA LINZ

Dissertation Committee

Dr. Bonnie A. Sturm, Chair

Dr. Judith A. Lothian

Dr. Pamela Galehouse

Approved by the Dissertation Committee

Bonnie A. Sturm Date 3-14-13

Judith Lothian Date 3/14/13

Pamela Galehouse Date 2/14/13

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Abstract

Purpose: The aim of the study is to explore and describe the experience of the worker on Assertive Community Treatment (ACT), an inter-disciplinary mental health outreach team, surrounding their efforts to facilitate social integration for the client with severe mental illness (SMI). ACT is very successful at assisting people with SMI to remain in the community. However, minimal focus has been devoted to improving social relationships. This area of concern regarding social integration warranted further exploration.

Background: The mental healthcare workers on ACT represent a variety of disciplines such as nurses, social workers, peer counselors, and substance abuse specialists. Working together, they provide comprehensive, long-term services in the homes for clients who are the most severely mentally ill in the community. As such, these frontline workers are very familiar with the difficulties and barriers associated with social integration for people with SMI.

Methods: This is a qualitative study using the Interpretive Description approach. Sixteen mental healthcare workers were individually interviewed about the topic of social integration; eight additional workers participated in two focus groups. The study participants represented workers on seven ACT teams in two Northeastern states and represented rural, suburban, and urban populations.

Results, Conclusions and Implications: Results of this research are that it is through caring and trusting relationships with the ACT workers that ACT clients engage in higher level treatment goals that lead to social integration. It is through office based educational groups and community activities that social skills are enhanced and opportunities for social interaction arise. Implications of this study suggest that the frequency of community based activities be increased, and that the clients be assisted and supported in their attempts to socially interact in the community with peers or people who are not mentally ill or both, around areas of shared interests and dependent on the clients' comfort with the interaction. In addition it is recommended that a social integration specialist be added to the ACT team so that the goal of social integration for people with SMI can be structurally incorporated into ACT as targeted focus of service.

Chapter I

INTRODUCTION

Aim of the Study

This interpretive descriptive study explores and describes the experience of workers on inter-disciplinary mental health community outreach teams based on the Assertive Community Treatment (ACT) model, and examines and describes the workers' efforts to facilitate social integration for their clients with severe mental illness (SMI). The mental healthcare workers on ACT teams represent a variety of disciplines such as nurses, social workers, psychiatrists, case workers, peer counselors, vocational specialists, family specialists, and substance abuse specialists. These workers provide intensive services for clients who are among the most severely mentally ill living in the community. As such, these frontline workers are very familiar with the difficulties and barriers associated with social integration for the person with SMI. The knowledge of their personal, first hand experiences adds valuable, practical knowledge of how this goal has been facilitated, as well as the obstacles that have been encountered surrounding their efforts to facilitate social integration for the client with SMI.

The Nurse on the Inter-disciplinary Team

Among the frontline workers, nurses play an integral role in ACT (Cuddeback & Shattell, 2010). A requirement of the ACT model is that nurses be included as team

members, (Bond, Drake, Mueser, & Latimer, 2001; Gold et al., 2003). In addition, some teams utilize psychiatric nurse practitioners as their psychiatric providers (Kane & Blank, 2004; Williams, Kukla, Bond, McKasson, & Salyers, 2009) and nurses have also functioned as team leaders (Williams et al., 2009).

Gold et al. (2003) suggested that ACT's success in delivering psychiatric services to people with SMI is based on the combined contributions of the nurses, social workers, case managers, and all other members of the inter-disciplinary team working in unison. A striking feature of this model is the strong working alliances among disciplines and the therapeutic relationships fostered between the recipient of services and members of the entire team. In a study that examined the benefits to the client's physical health by including an Advanced Practice Nurse (APN) and peer counselor on ACT teams, Kane and Blank (2004) wrote, "It is the interaction of the whole team that is responsible for the positive outcomes so often observed" (p. 557). It is common for the activities of team members to overlap, which may result in a blurring of roles (McAdam & Wright, 2005). The psychologist performs the duties appropriate to his or her license, but in addition, might also take on a case management role, or a nurse and a social worker will perform duties specific to their license, but also spend time preparing the client for a job or housing interview. The goal of the inter-disciplinary team is the client's recovery, and close collaboration between team members is essential to reach their shared goal (Gold et al., 2003).

Washington State's WA-PACT Program Standards document (2007) delineated the nature of ACT's approach by exchanging the term "multi-disciplinary"

for the term “transdisciplinary” explaining that team members share roles (still acting within the confines of their license), combine expertise, and move beyond specific disciplinary identifications (Washington State Program of Assertive Community Treatment [PACT] Program Standards, 2007). Decisions are made jointly and regularly through team meetings. Thus, although the discipline of nursing is an integral component of ACT, investigating the role of the nurse alone in facilitating social integration in the client with SMI would not have sufficed in presenting the whole picture, as the effort is, by design, a team approach.

Definition of Severe Mental Illness (SMI)

Severe mental illness (SMI) has been defined as a mental illness that produces severe psychiatric disabilities, with schizophrenia being the most common psychiatric diagnosis in this group (Bond & Campbell, 2008). Bipolar disorder, major depression, and severe anxiety disorders may also be included in this category depending on the severity of impairment in functioning (Bond et al., 2001; National Institute of Mental Health [NIMH], 1999).

Phenomenon of Interest

After deinstitutionalization in the 1960’s the community, as opposed to the psychiatric hospital, has become the place in which needed mental healthcare supports and services are provided to people with SMI (Drake, Green, Mueser, & Goldman, 2003; Trute, Teft, & Segall, 1989). Without adequate supports many of the people with SMI released from the state hospitals become homeless, or filter into the

prison system (National Alliance on Mental Illness [NAMI], 2010; Torrey, 1997). One such effective support is the community interdisciplinary mental health outreach team. The original service was a community outreach team called Assertive Community Treatment (ACT) developed in the 1970's by Stein and Test in order to address the needs of people with SMI who did not attend mental health clinics, were not able to function independently in the community, and were socially isolated (Bond et al., 2001; Drake et al., 2003; Stein & Test, 1980). The original team was composed of eighteen staff members, half of whom were nonprofessional workers who had formally been hospital psychiatric aides. Since the formation of the original ACT team, team staffing has become smaller and more representative of professional disciplines (Stein & Santos, 1998) such as psychiatrists, social workers, nurses, vocational specialists, and may contain other specialists such as psychologists, case managers, nurse practitioners or peer counselors (Bond et al., 2001; McEvoy & Richards, 2007; Rosen, Mueser, & Teeson, 2007; Stanhope & Matejkowski, 2010; Stull, McGrew, & Salyers, 2010; Veldhuizen, 2007; Williams, 2005; Williams et al., 2009). Staffing may vary depending on the population served, for instance, substance abuse specialists are employed on teams serving dually diagnosed individuals.

ACT models have proliferated and may be known under a variety of names such as "mobile treatment teams", "assertive outreach", and "continuous treatment teams" (Bond et al., 2001). Another broadly used term for ACT is Program of Assertive Community Treatment (PACT). There is no difference between ACT and PACT, and these terms have been used interchangeably (NAMI, 2011). For the

purpose of this research study, the term “ACT” is used to refer to both Assertive Community Treatment (ACT) and Program for Assertive Community Treatment (PACT) teams.

ACT as a community outreach team provides intensive holistic services to people with SMI who meet criteria providing evidence that the client is unlikely to seek treatment independently or by less intensive modalities (Bond et al., 2001; Salyers & Tsemberis, 2007). ACT provides medication management, crisis intervention, social services, and whatever else is necessary, in order to help facilitate successful community integration for clients with SMI (Bond et al., 2001; McEvoy & Richards, 2007; Rosen et al., 2007; Stanhope & Matejkowski, 2010; Stein & Santos, 1998; Stull et al., 2010; Veldhuizen, 2007; Williams, 2005; Williams et al., 2009). Thus, the community outreach mental healthcare worker goes to where the client is. Unlike the usual provision of mental healthcare services at clinics or mental health offices, most meetings occur in the client’s home (Bond et al., 2001). Attendance in day treatment groups is not required in order to receive services (Carton, Young, & Kelly, 2010). Although this type of intensive service may be necessary for people with SMI who are reluctant to seek and maintain treatment on their own (Bond et al., 2001; Salyers & Tsemberis, 2007), it is possible that receiving all treatment in the home contributes to social isolation and lack of social interaction within the community.

ACT is successful at improving housing and psychiatric conditions, establishing supportive relationships between staff members and their clients, and

helping with day to day needs (Calsyn, Morse, Klinkenberg, Trusty, & Allen, 1998; Carton et al., 2010; Krupa et al., 2005; Stull et al., 2010). However, minimal focus has been devoted to improving the social relationships of ACT's clients either with other people with SMI (Carton et al., 2010) or in the greater community (Angell, 2003; Calysn, et al., 1998; Krupa et al., 2005). This area of concern regarding social relationships warranted further exploration. This research study explored the manner in which ACT workers promote social interaction and facilitate social integration in the community.

Research Questions

This research was designed to answer the question: What is the experience of the worker on an Assertive Community Treatment (ACT) team surrounding their efforts to facilitate social integration for the client with severe mental illness (SMI)?

The following questions served as a guide to explore this experience:

- a. How do individual ACT team members define the concept of "social integration"?
- b. What methods have been used by ACT team workers in order to attempt to facilitate social integration in the community?
- c. What do ACT team workers perceive to be obstacles or barriers in facilitating social integration for their clients?
- d. What innovative suggestions can ACT team workers offer for to enhance social integration for their clients with SMI?

Justification for Studying the Phenomenon

Carpenito-Moyet (2008) defined social isolation as a, “state in which a person or group experience a need or desire for increased involvement with others, but is unable to make that contact” (p.634). Hawthorne (2006) referred to the term social isolation as, “living without companionship, social support, or social connectedness” (p.523). Cacioppo and Hawkley (2009) wrote that it is perceived social isolation that is known more colloquially as loneliness. When isolation is sought out as a form of “aloneness” in order to facilitate reflection, or to increase concentration, isolation does not result in loneliness (Peplau, 1955). In other words, it is the perception of social isolation that causes loneliness. Perceived social isolation has also been defined as loneliness and a lack of perceived social support (Cornwell & Waite, 2009). For the purpose of this research, the term “social isolation” refers to a state of being unintentionally alone, with a lack of fulfilling social connection, resulting in the subjective experience of loneliness and distress.

Social neuroscience theory posits that humans have evolved as social beings and as such, need relationships (Cacioppo & Patrick, 2008). Numerous studies have shown that when social isolation is not by choice, it has adverse effects on mental and physical health (Berkman & Syme, 1979; Cacioppo, Hughes, Waite, Hawkley & Thisted, 2006; Cornwell & Waite, 2009). A study on perceived loneliness in older adults found that loneliness, and especially chronic loneliness, was a risk factor for mortality (Shiovitz- Ezra & Ayalon, 2010). A meta- analytic review by Holt-Lunstad, Smith, and Layton (2010) looked at 148 studies investigating the link between social

relationships and mortality risk and found that the influence of social relationships on mortality is comparable to risks such as smoking and excessive drinking.

While these studies have affirmed the negative effects of social isolation on physical health in the general population, research in this area has not yet been conducted in regards to the severely mentally ill. It is well known that a frequent and consistent complaint of community living people with SMI is the experience of social isolation and loneliness (Chernomas, Clarke, & Marchinko, 2008; Davidson, et al., 2004; DeNiro, 1995; Herman, Onaga, Pernice-Duca, Oh, & Ferguson, 2005; Perese & Wolf, 2005). Except for increased rates of cigarette smoking among people with schizophrenia, when controlling for body mass index, the other contributing factors associated with the increased coronary heart disease found in people with SMI remains unclear (Goff et al., 2005). Given the fact that people with SMI have been shown to have a reduced lifespan of about 25 years compared to the general population (Colton & Manderscheid, 2006; Newcomer & Hennekens, 2007), it is possible that social isolation may contribute in some manner to the shortened lifespan as has been suggested in the general population (Holt-Lunstad et al., 2010; Shiovitz- Ezra & Ayalon, 2010).

Besides the negative effects on physical health on the general population, social isolation has also been shown to affect the mental health of people with SMI. Davidson (2007) suggested that as a society we should not expect people with SMI to live their life in the community alone. Like the rest of us, people with SMI need companionship. It is through interpersonal relationships and mutual supports that the hardships caused

by mental illness can be mitigated (Davidson, 2007). In a study investigating the social networks of people with recent onset schizophrenia, Horan, Subotnik, Snyder, and Nuechterlein (2006) found that people with SMI who had smaller social networks had higher levels of positive symptoms such as auditory hallucinations, than people with SMI who had larger social networks (other than family members) even though all of these individuals were consistently taking the same monthly or bi-monthly psychiatric medication injections and had a similar diagnosis. A study investigating types of social support, psychiatric symptoms, and maintenance of housing in people with SMI found that social support from friends and family was a factor in reducing psychotic symptoms and that social support from friends and family was found to be causally related to length of time in stable housing (Calsyn & Winter, 2002).

Several researchers suggested that interventions should be undertaken to facilitate the social lives in people with SMI so that chronic psychiatric disability might be prevented and the collateral damage of the disease lessened (Heinssen & Cuthbert, 2001; Horan et al., 2006). Garety, Kuipers, Fowler, Freeman, and Bebbington (2001) offered that people with SMI who are socially isolated are more likely to suffer from delusions. In addition, social isolation has been linked to the lack of insight into one's mental illness (White, Bebbington, Pearson, Johnson, & Ellis, 2000). In a qualitative study investigating reasons for high rates of psychiatric recidivism and re-hospitalization, the high service users consistently expressed that social isolation and exclusion from mainstream activities was the reason for their high hospital usage (Mgutshini, 2010).

The concept of quality of life (QOL) is an important consideration in regard to the provision of healthcare and social policy. As such, tools have been developed to measure the QOL in people with SMI. These tools typically include a measure for social relations among other concerns such as housing and physical health (Prince & Prince, 2001; Test, Greenberg, Long, Brekke, & Burke, 2005). Ware, Hopper, Tugenberg, Dickey, & Fisher (2008) considered QOL a key concern for people with SMI in terms of social integration. In developing ACT, Stein and Test (1980) put forth that an important function and goal of ACT was to improve the QOL in their clients with SMI and to provide them with support for daily living, leisure, and to improve relationships by providing social skills training. After 30 years of ACT, clients continue to complain of social isolation and loneliness (Angell, 2003; Calsyn et al., 1998; Krupa et al., 2005; Prince & Prince, 2002; Scheyett, Pettus-Davis, & Cuddeback, 2010; Stull, et al., 2010), this apparent deficit in terms of ACT's own QOL goals regarding social relation warranted further investigation. Yanos, Barrow, and Tsemberis (2004) suggested that the processes used by programs to promote social interaction within the community for individuals living independently has not yet been, but should be, explored. Stull et al. (2010) suggested that although social relationships are important to people with SMI, and the significance of social relationships is consistent with the philosophy of treatment programs such as ACT, this treatment approach has not yet been shown to be efficacious in facilitating social relationships and social networks; and, they suggested that future studies should examine the ways in which this treatment model strives to facilitate social relationships.

Relevance for Nursing

In keeping with the strong tradition of community based nursing (Fee & Liping, 2010), psychiatric nurses provide care in the community for many of the 2.6% of the population of the United States that is diagnosed with a SMI at in any given year (National Institute of Mental Health [NIMH], 1999). Mental Health Nurses are valued members of inter-disciplinary outreach teams and work closely with other professions in providing integrated support for individuals with SMI who live in the community (Bond et al., 2001; Gold et al., 2003; McAdam & Wright, 2005; McEvoy & Richards, 2007; Rosen et al., 2007; Stanhope & Matejkowski, 2010; Veldhuizen, 2007; Williams, 2005; Williams et al., 2009). In addition, APNs have been utilized successfully in the inter-disciplinary outreach model (Kane & Blank, 2004; Stull, et al., 2010; Williams et al., 2009). An example of the importance of the APN role on ACT teams is demonstrated in the state of Washington where in their delineation of standards for psychiatric providers on their ACT Teams, specified that either psychiatric nurse practitioners or psychiatrists could function as the team's psychiatric provider (Washington State Program of Assertive Community Treatment [WA-PACT] Program Standards, 2007).

The nurse theorist Orem (2001) wrote about the importance of having “agency”, to be able to engage in the community, to have mutually satisfying relationships, and to have the ability to communicate interpersonally with others. Peplau (1992), considered the mother of psychiatric nursing (Haber, 2000) taught that the nurse's therapeutic use of “self” with the person with SMI, would create a

synthesis, enabling increased integrated human functioning for the patient. Peplau (1997) also believed that interpersonal relationships and connectedness with others are essential throughout an individual's life.

Nurses and other workers need to engage and work with the often resistant clients served by the inter-disciplinary outreach team. Therefore, it is valuable for nursing to know the ways in which mental healthcare workers on ACT teams developed trusting, socially engaging, and therapeutic relationships with their clients. Understanding the methods used by team members that were effective in enriching the social skills of this patient population supports the goal of facilitating social integration for people with SMI in the community. Knowledge of the obstacles faced by workers (including nurses) enables nursing to develop focused solutions. Many people with SMI desire and enjoy reciprocal relationships (Lenucha, Kinsella, & Sumsion, 2008). With the needed supports to facilitate social skills (Hogarty & Wieland, 2005; Wilson, Flanagan, & Rynders, 1999), social interaction and community integration are reasonable goals for recovery in people with SMI (Ware et al., 2008; Wong & Solomon, 2002).

Researchers Perspective

I became interested in conducting research that may contribute to improving the quality of assistance that is provided to people with SMI who live in the community, in part through my professional experiences. I have come to realize that people with SMI often continue to have many unmet psychosocial needs. I am an Advanced Practice Psychiatric Mental Health Nurse with over twelve years' experience in community

mental health nursing. I worked as a registered nurse for three years on an ACT team serving people with SMI and substance abuse issues, and as an APN for two years on an inter-disciplinary team based on ACT serving people triply diagnosed with SMI, HIV, and substance abuse. These experiences provided me with enough understanding of the work that is involved as a member of an inter-disciplinary outreach team serving clients with SMI to enhance the rapport I was able to achieve with members of the ACT teams.

Prior to becoming a nurse I worked for 17 years as a recreational specialist in a 200 bed residential program for the mentally ill, and facilitated social activities, community outings, and led art and photography groups for people with SMI. My personal bias is that I believe that through the use of skilled therapeutic relationships with mental health workers, combined with planned social interventions, clients with SMI who live in the community can lead a life with satisfying social relationships and a sense of community belonging. In the course of conducting this research study I needed to maintain an ongoing awareness of this view and at the same time, remain fully open to the view points and experiences of the study participants.

Because the population served by ACT is particularly difficult to engage, I was interested in finding out if the emotional relationship, the “offering of self” by the worker, might be an aspect of the way the patient initially engages socially with the worker, and later with others. I was also interested in finding out how the worker engaged the resistant client, encouraged family or peer relationships, helped the client to develop social skills, and facilitated community involvement. I believed that it was

the frontline worker who was best situated to understand and explain the barriers faced in attempting to facilitate social integration for clients served by ACT.

Chapter II

LITERATURE REVIEW

People with SMI have long been excluded from society. Foucault (2006) began his history of European society's treatment of the mentally ill with the description of the "ship of fools" a metaphor for the 14th century practice in which the mentally ill were regularly expelled from their walled cities and entrusted to the care of riverboat men who would ferry them far downstream to be put ashore in unfamiliar places to wander and beg. In the 15th century, North Africa influenced European care of the mentally ill by providing examples of compassionate hospital care (Livianos, Miguel, & Moreno, 2010). However, by the 17th and 18th centuries, the mentally ill, criminals and other undesirables were separated from society and sequestered together in workhouses and institutions originally built to hold the leprous population. By the end of the 18th century, mental illness came to be viewed as a medical concern and institutions devoted to the care of the mentally ill were established (Foucault, 2006).

The compassionately run institutions in Europe became the model for the early hospitals in the Colonial United States (Stein & Santos, 1998). The small number of humanely run and religiously affiliated hospitals were not able to provide care for the immigrant masses, and once again people with mental illness were either locked at home, wandered the streets, or were jailed (Stein & Santos, 1998). In response to the deplorable treatment of the mentally ill in the United States, in the mid-19th century,

Dorothea Lynde Dix successfully advocated for individual states to build institutions to humanely care for the mentally ill. The policy of societal isolation of the mentally ill was bolstered by the Eugenics movement which championed the isolation of what was considered a defective population. By the 1950's, the state institutions were grossly over crowded with a population of one half million individuals (Stein & Santos, 1998). These institutions have been described as ineffective, inhumane, and inefficient (Klerman, 1977).

Deinstitutionalization

In the 1960's public opinion turned against the state psychiatric institutions. In order to comply with the changes mandated to make these institutions more humane and efficient, the states faced overwhelming costs. At the same time, the federal program of Medicaid was instituted in 1965. Medicaid would not pay for state hospitalization, but would pay for the community treatment of the mentally ill (Stein & Santos, 1998). In addition, the use of newer and more effective psychiatric medications gave hope that patients with SMI could be managed in the community (Klerman, 1977). Thus, the combination of public opinion, an opportunity for states to save money by shifting costs for the care of the mentally ill to the federal government (Klerman, 1977; Stein & Santos, 1998) as well as psychopharmacological advances led to the policy of deinstitutionalization in the 1960's and 70's (Aviram & Segal, 1973; Klerman, 1977).

People with SMI were released into communities without the needed supports leading to homelessness, incarceration, and cycles of psychoses and re-hospitalizations

(Drake et al., 2003; Klerman, 1977; Stein & Santos, 1998; Torrey, 1997). Although the physical proximity of people with SMI in the community was accepted, the social integration of the mentally ill did not occur. Socially excluded, people with SMI lived on the margins and became socially isolated (Aviram & Segal, 1973; Klerman, 1977). Although socially excluded, people with SMI prefer to live in the community as opposed to long term hospitalization (Hobbs, Newton, Tennant, Rosen, & Tribe, 2002). Davidson, Haglund, et al. (2001) suggested that although appearances may be to the contrary, individuals with SMI have a strong desire for social relations despite the numerous obstacles they face in attempting to connect with others.

Social Isolation

Social isolation is considered an aberrant condition. The ability to connect with others has long been held as an important and natural component of human existence. The noted psychiatrist and theorist, Sullivan (1953) wrote, "man requires interpersonal relationships, ...being cut off is perhaps not as fatal as for an animal to be cut off from all sources of oxygen; but the lethal aspect of it is nonetheless well within the realm of correct referential speech" (p. 32). Peplau (1997) suggested that interpersonal relationships are needed as the very foundation of life. The philosopher Martin Buber wrote, "The individual is a fact of existence insofar as he steps into a living relation with other individuals....The fundamental fact of human existence is man with man" (Buber, 1948/1966, p.113).

Severe mental illness has been inextricably linked to social isolation. In fact, the DSM IV includes disruption of interpersonal relations as part of the criteria for the

diagnosis of schizophrenia (American Psychiatric Association [APA], 2000). Social withdrawal is considered one of the negative symptoms of schizophrenia, a serious biological disease (Andreasen, 1979; Crow, 1985).

Warren's (1993) concept analysis of social isolation in the general population put forth the constructs of stigma, alienation, loneliness, aloneness, and powerlessness as subheadings that described the full range of the meaning of the phenomenon. In a review of the literature in relation to social isolation and mental illness, the constructs of stigma, alienation and loneliness re-emerge describing the meaning and causes of social isolation as it relates to the experience of people with SMI. Stigma has been studied predominantly by quantitative measures, whereas alienation and loneliness in the mentally ill have been studied using predominantly qualitative methods.

Stigma. In the late 1950's and the 1960's, the mental health field was influenced by sociology's conceptualization of social isolation and the mentally ill through the investigation of "stigma" and its impact on social isolation. Social processes were incorporated into the understanding of mental illness. In *Asylum*, Goffman (1961) presented his ethnographic study of patients in a mental hospital. He observed a process by which individuals with psychiatric difficulties enter a mental hospital and discover that not only have they lost contact with reality and lost control of their behavior, they have also lost their identities as "normal" persons. They are viewed and view themselves differently than before as the result of being labeled as mentally ill, a highly stigmatized societal role. They may attempt to regain access to

society however, once stigmatized, true access to community is never fully regained (Goffman, 1963).

Influenced by Goffman and other sociologists of the mid-century, Scheff (1963) developed the *labeling theory*. Scheff (1963) said in effect, that the mentally ill, once diagnosed, labeled, and stigmatized, consciously and unconsciously “act” the mentally ill role they have been labeled with. The labeled individual internalizes the role of mental illness based on society’s expectations of mentally ill behavior learned since childhood and is locked into that role by society’s stigma toward the person labeled as mentally ill. These radical assertions, widely held in the 60’s, brought about a firm rebuttal in the 1970’s. Gove (1970) in particular, rejected the labeling theory. He firmly believed that the mentally ill person’s behavior caused others to view them in a negative light and it was continued bad behavior that kept them in a stigmatized position, and not the other way around. It was not stigma that caused mental illness, but mentally ill behavior that caused stigma.

The labeling theory initiated a heated debate about the role and cause of stigma as it affected people with SMI. Link (1987), in an attempt to reconcile the opposing viewpoints developed the *modified labeling theory* to explain stigma and its isolating effects on individuals with mental illness. The modified labeling theory posits that stigma is a serious force in the lives people with SMI, significantly affecting their acceptance in society and in the perceptions of themselves. This differed from the labeling theory in that the modified labeling

theory did not support the notion that individuals with SMI would act in order to fulfill a label imposed by societal expectation. However, the experience of external stigma and the internalization of stigma would affect the self-esteem in individuals with SMI and cause these individuals to disengage from social situations, thus increasing their social isolation (Link, 1987; Link, Cullen, Struening, Shrout, & Dohrenwend, 1989; Link, Phelan, Bresnahan, Stueve, & Pescolido, 1999).

Based on the modified labeling theory, research has continued on the effects of stigma and internalized stigma as a major cause of social isolation for people with SMI. Aviram and Segal (1973) noted that from the beginning of deinstitutionalization, people with SMI had been excluded from community integration due to the public's attitude toward them. Rosenfield (1997) found that only interventions that provided needed services to the mentally ill and reduced stigma within communities could effectively change the quality of life for people with SMI.

Schulze and Angermeyer (2003) conducted focus groups with individuals with schizophrenia in order to ascertain their experience of stigma. They found that 49% percent of their study participants believed that their experience of social isolation was caused by the stigma related toward their diagnosis. Even when asymptomatic, they experienced stigma. Stigma or the process of labeling, relates to Buber's (1937/1970) philosophical treatise describing the "I and Thou" relationship. Buber (1937/1970) asserted that to truly be in relation to another, the relationship must be as I /Thou. One person in their entirety views another in their entirety. However, when a person has been stigmatized, they are no longer seen as a full human being, they become

objectified, the object becomes an “it” and the relationship becomes “I /It”. The stigmatized person is not seen as an individual apart from their label. When this occurs, no truly reciprocal relationship between two beings is possible.

Alienation. The concept of alienation has been applied to the field of mental health in order to explain the phenomena of social isolation. Erdner, Magnusson, Nystrom, and Lutzen (2005) defined alienation as, “an estranged relationship between individuals and their social environment” (p.374). DeNiro (1995) described alienation as a sense of non belonging, a feeling that drives a person to withdraw from a society that they cannot comfortably participate in with any measure of solidarity. Davidson and Stayner (1997) offered the term “empty shell” as a term that has been used clinically to describe the person with schizophrenia; lacking in social skills, socially isolated, taken care of by others but lacking the ability for reciprocal relationships. Although they might reside in the community, community life does not bring connection; often the person with SMI views their neighbors with as much suspicion as they themselves are viewed (Agget & Goldberg, 2005). Here, alienation relates to Buber’s (1937/1970) description of the I and Thou relationship. It is the alienated person with SMI who in effect, also objectifies and withdraws from the larger society that they have lost relation to; the relationship becomes “it /it”.

Loneliness. Brown (1996) compared living situations and their relationship to loneliness for people with SMI. The study found that this population experienced high levels of loneliness whether they lived with others or alone, suggesting that loneliness is an ongoing and pervasive experience for this population. In a study exploring the

experiences of loneliness in individuals with SMI who live alone in the community, Nilsson, Naden, and Lindstrom (2008) found that loneliness had a strong relation to the experience of suffering. The loneliness described by the study participants is an existential loneliness, ever present, coloring the experience and meaning of their lives. Granerud & Severinsson (2006) also found loneliness to be a main theme in individuals with SMI struggling to integrate socially into the community. Individuals felt alone, even when with people (Erdner, Nystrom, Severinsson, & Lutzen, 2002).

In contrast, individuals with SMI reported that loneliness was relieved by engaging in creative endeavors, visual arts, music, and writing (Nilsson et al., 2008), and also through relationships with pets (Erdner, Andersson, Magnusson, & Lutzen, 2009). Although several studies found that relationship with God was conflicted and ambivalent (Erdner et al., 2009; Nilsson et al., 2008), other studies have shown spirituality to be a healing force in the lives of individuals with SMI (Bussema & Bussema, 2007; Davidson, Stayner, et al., 2001).

Chernomas et al. (2008) studied the relationships of women with SMI and their support systems, finding that it was "reciprocity" in relationships that they deemed most satisfying. In a study of supported socialization, Davidson, Haglund et al. (2001) found that people with SMI were not empty shells and could engage with others as long as they felt that the relationships were reciprocal. The study participants desired to feel cared about as unique individuals and not as recipients of charity. This finding supported hope for recovery for people with SMI. It is through the reduction of external stigma that alienation, loneliness and internalized stigma could be reduced.

True reciprocity in relationship is the I and Thou relationship described by Buber (1937/1970).

From Social Isolation to Social Integration

Social integration for people with SMI is consistent with the original goals of ACT and with the philosophy of *recovery* from mental illness of the past several decades. Severe mental illness was viewed throughout most of the twentieth century as having an inevitable downhill course (Wexler, Davidson, Styron, & Strauss, 2007). A more positive attitude towards recovery from mental illness was supported by a number of studies showing that the illness may remit entirely, or symptoms may become manageable and do not necessarily result in the dire outcomes once expected (DeSisto, Harding, McCormick, Ashikaga, & Brooks, 1995; Harding, Brooks, Ashikaga, Strauss & Breier, 1987; Harrison et al., 2001; Huber, Gross, Schuttler, & Linz, 1980; Silverstein & Bellack, 2008).

The philosophy of the recovery movement has been advocated as a guide for mental health treatment in the United States, and has been described as, “The process in which people are able to live, work, learn, and participate fully in their communities... recovery is the ability to live a fulfilling and productive life despite a disability” (The President’s New Freedom Commission on Mental Health, 2003, p. 7). A recent definition of recovery from mental illness and substance use is a “process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential” (The Substance Abuse and Mental Health Services Administration [SAMHSA], 2011, p.1) The dimensions through

which this goal may be attained are through managing one's health and illness, having a stable place to live, finding purpose in life through daily activities, and participating in the community through relationships and social networks (SAMHSA, 2011).

Recovery is not a linear process, it occurs in degrees and stages, utilizing different paths depending on personal characteristics and the effects of the social environment (Lieberman & Kopelowicz, 2005). The consumer's desires for a better life, self-determination, and desires for social inclusion are supported (Davidson, O'Connell, Tondora, Styron, & Kangas, 2006). Social isolation is no longer seen as an inevitable consequence of SMI; to the contrary, social integration is considered a possible and accepted goal.

In a qualitative study exploring the meaning of social integration, Ware, Hopper, Tugenberg, Dickey, and Fisher (2007) viewed social integration in the context of opportunities offered by the environment and capacities possessed by the person with SMI. It is understood to be an important component of community integration and refers to the engagement with a social network that includes reciprocal social relationships with others in the community in non-clinical settings (Wong, Matejkowski, & Lee, 2011). Ware et al., (2007) defined social integration as, "A process, unfolding over time, through which individuals who have been psychiatrically disabled increasingly develop and exercise their capacities for connectedness and citizenship" (p.471). Connectedness with others includes people with SMI and people who do not have a psychiatric disability. It is important is that these relationships offer

companionship, access to resources, and provide social support in the context of larger, reciprocal relationships (Ware et al., 20). 07

Assertive Community Treatment (ACT)

ACT was created by Stein and Test (1980) in Madison, Wisconsin in the early 1970's as a radical experiment in the provision of integrated community based mental healthcare as an alternative to the psychiatric hospital. This model was designed to assertively assist people with SMI who live in the community, who may be socially isolated with unmet medical and psychiatric needs, poor quality of life (Stein & Santos, 1998) and repeated psychiatric hospitalizations (Salyers & Tsemberis, 2007; Stein & Santos, 1998). The individuals best served by ACT are people with SMI who are unlikely to seek treatment (Bond et al., 2001; Salyers & Tsemberis, 2007), generally missing MD or mental health clinic appointments. ACT is committed to changing the treatment strategy from "preparing patients for community life to maintaining patients in community life" (Stein & Test, 1980, p. 397). The goals of ACT include increased client functioning, higher quality of life, community and social integration, and helping clients remain stable in the community (Stein & Santos, 1998). In order to meet these goals, ACT is responsible for assisting with housing, food, and other essential needs, as well as providing support and encouragement for their clients to remain engaged with their communities and to be involved in social activities (Stein & Test, 1980).

ACT as a treatment for people with SMI in the community is considered evidence based (Bond et al., 2001; Bond, Salyers, Rollins, Rapp, & Zipple, 2004).

ACT has been shown to reduce hospital costs (Bond et al., 2001; Burns et al., 1999;

Harvard Mental Health Letter, 2011), and increase housing stability (Mueser, Bond, Drake, & Resnick, 1998). Compared to traditional case management models, ACT has been shown to increase the medication adherence in clients who are dually diagnosed with SMI and substance abuse (Manuel, Covell, Jackson, & Essock, 2011).

The ACT model has proliferated in both rural and urban communities across the United States, and has been disseminated to Canada, Great Britain, Australia, (Gold et al., 2003; Stein & Santos; 1998), Sweden (Falk & Allebeck, 2002) the Netherlands (Veldhuizen, 2007), Germany, Denmark (Harvard Medical Letter, 2011), and Japan (Horiuchi et al., 2006).

One of the hallmarks of ACT is the relationship that develops between the client, the primary worker, and the entire inter-disciplinary team. The ACT client and their primary worker have a strong and continuous relationship in which the person with SMI is known and understood as an individual. Relationships are established between all of the team members and each team client, with these relationships providing additional interaction and support (Carton et al., 2010; Gold et al., 2003; Krupa et al., 2005; Stanhope & Matejkowski, 2010).

The Dartmouth Assertive Community Treatment Scale (DACTS) (Teague, Bond, & Drake, 1998) has been the instrument used to measure the degree of fidelity to the original ACT model. Fidelity to ACT includes having a small caseload (1.10 ratio), team approach, assertive engagement, daily program meeting, practicing leader, staff continuity, psychiatrist, nurse, substance abuse specialist, vocational specialist, explicit admission criteria, intake rate, full responsibility, crises responsibility, hospital

admissions responsibility, discharge planning responsibility, time- unlimited services, in-vivo services, no drop out, service intensity, contact frequency, work with support system, individual substance abuse treatment, group substance abuse treatment, and dual disorder model (Salyers et al., 2003; Teague et al.,1998; Winter & Calsyn, 2000).

The Journal of the American Psychiatric Nurses Association devoted an entire issue to ACT in which they published an updated tool, the TMACT, to measure fidelity to the ACT model (Monroe-DeVita, Teague, & Moser, 2011). The changes reflect influences of the recovery philosophy and other evidence based advances. The changes made include the use of advanced practice nurse practitioners, vocational specialists, and peer specialists, in order to reflect new staffing policies. New practices such as supported employment, cognitive behavioral therapy, and family psycho education have also been added (Monroe-DeVita, et al., 2011). ACT teams vary, and depending on state standards often do not meet full fidelity to the model (Gold et al., 2003; Mueser, et al., 1998). Adaptations have been made for targeted populations, varying geographical needs (Mueser et al., 1998), and to better adhere to recovery principles and evidence based practices (Monroe-DeVita, et al., 2011). Forensic Assertive Community Treatment (FACT) is an example of an ACT team especially targeted for people with SMI who have a forensic history (Harvard Mental Health Letter, 2011). Higher fidelity scores have been associated with financial savings through the reduction of hospital usage (McGrew, Bond, Dietzen, & Salyers, 1994; McHugo, Drake, & Teague, & Xie, 1999).

ACT and Social Integration

Researchers have used qualitative and quantitative methods to study aspects of social integration in relation to ACT from both the standpoint of community interaction and the ways in which ACT clients experience social relationships.

Using stigma and the modified labeling theory as a framework (Link, 1987; Link et al., 1989; Scheff, 1963), Prince and Prince (2002) studied perceived stigma and its relationship to community integration for people with SMI who receive ACT services by using sequential multiple regression procedures. This study used a participatory research approach and included individuals with mental illness in the planning and interviewing process. Community integration was separated into the constructs of physical integration (frequency of interactions outside of the home), social integration (social interaction with non-mentally ill neighbors), and psychological integration (sense of belonging, investment and connection to the community). The study participants (ACT clients) scored low on measures for physical and social integration and moderate on psychological integration. Although the study participants did endorse a belief that people with SMI are devalued and discriminated against, perceived stigma was not correlated with physical or social integration, but did explain a portion of the variance for psychological integration (Prince & Prince, 2002). It was primarily the level of the clients psychosocial functioning and perceived social support that had the largest influence on community integration. The study supports the need for the development of interventions to

increase psychosocial function and client support, and to address internal and external stigma in order to better facilitate ACT clients' integration into the community.

In a qualitative study, Krupa et al. (2005) used a participatory research approach, engaging six ACT clients in rural Canadian communities to join two university researchers as a research team utilizing focus groups to elicit client's perspectives on how ACT promotes community adjustment. The study participants expressed the belief that it was the relationship with the primary counselor and the team that was most important. Feeling cared about and encouraged led to an enhanced ability to function out of the hospital and in the community. The process of engaging with ACT staff and developing a trusting relationship unfolded and changed over time, depending on the needs of the client. Trust in the relationship was determined to be crucial in preventing the social isolation that might develop otherwise. For clients with small social networks, the team provided desired social interaction.

In supporting community integration, ACT was seen by the study participants to assist with the daily challenges of community living while managing symptoms of mental illness. One intervention deemed helpful was keeping a journal to document client concerns that could later be addressed with staff. Although most study participants felt positively about ACT services, the clients also reported continued difficulties with isolation, the depth of community participation, poverty, and perceived stigma. The study participants believed that ACT workers were constrained in their efforts to facilitate greater community integration due to work related demands and a general lack of focus on this issue.

Focus groups were used in a qualitative study aimed at gathering staff perspectives on the ways in which forensic ACT teams affected community change (Scheyett et al., 2010). The study participants reported that due to the presence of forensic ACT teams in the community, both physicians and landlords became more welcoming to their clients, goods were more easily accessed through increased donation, and collaboration between forensic ACT and other community mental health and service agencies improved. Additionally, a reduction in stigma was perceived to have occurred, both with workers in the criminal justice system who were engaged with the forensic ACT clients, and in the community.

The process that facilitated the community change was the building of trusting and collaborative relationships with community agencies by the forensic ACT staff. In addition, the ACT workers educated individuals in the community about mental illness through simple dialogue. The findings of this study may not be transferable to other ACT teams assisting people with SMI who do not have a forensic history.

Several studies looked at social integration by examining the social relationships of ACT clients. Calsyn et al. (1998) conducted randomized experiments to compare the effectiveness of ACT serving homeless mentally ill clients against other treatment modalities, such as drop in centers and traditional outpatient settings on improving social relationships. They also compared a traditional ACT team against an ACT team that utilized paraprofessionals as an adjunct to staffing in order to further assist homeless ACT clients. The researchers hypothesized that ACT's in vivo service provision and involvement with client's interpersonal conflicts; as well

as possible introduction to community members by the paraprofessionals, would lead to a larger social network for the ACT clients. However, using MANCOVAS as statistical analysis, neither the ACT teams designed to assist the homeless, nor the teams with the added use of paraprofessionals, were found to expand the client's natural social network as compared to the other treatment modalities. What was increased was the amount of professionals that the client interacted with.

Without utilizing specific, goal oriented interventions to increase the client's social relationships on these ACT teams, social relationships were not facilitated. The disruption of social relationships caused by homelessness in this unstable population, regardless of treatment type, was not addressed, and several of the instruments used reported low reliability. In addition, the findings of this study may not be transferable to ACT teams serving clients already in stable housing, a situation that may be more conducive toward the formation and maintenance of social relationships.

Angell (2003) used a grounded theory approach to investigate the contexts and processes in which social relationships developed among ACT clients. The study participants were people with SMI receiving services from ACT. Additionally, two staff persons were interviewed in order to augment the client's perspective but not to represent a full workers perspective regarding social relationships and clients of ACT.

Angell (2003) found that the ACT clients developed non kin social relationships through three routes. One path was through the development of social relationships afforded by the client's participation in structured group activities such as participation in a mental health program. Also in this category, housing designated

for the mentally ill provided opportunities for developing social relationships. Another path was through ACT interventions such as organized recreational experiences, or engineered relationships in which ACT workers introduced clients to each other. ACT staff promoted social relationships by introducing clients that staff perceived as potentially compatible. Funds were offered so that the clients could meet and afford to share a social activity together. At times, staff also introduced clients to non- mentally ill volunteers in the community for socialization purposes (Angell, 2003). The third route toward socialization was through efforts undertaken by the client to increase social contacts with people without a mental illness, a path often fraught with difficulty.

The majority of the study participants found it advantageous to form social relationships with other people with SMI due to their shared bond of the experience of mental illness and the reciprocal relationships that this shared understanding and support enabled. On the other hand, several participants, although mentally ill themselves, viewed people with SMI in a negative light and desired to have relationships with “normal” people who had the capacity to provide consistent reciprocity in the relationship. Angell (2003) noted that although social integration is a goal of ACT, the ACT model does not have an embedded method of facilitating social integration and instead uses informal approaches in addressing issues of social isolation and loneliness in their clients.

The perspectives of both staff and clients were sought in a mixed method study investigating the definition of success and failure in ACT (Stull et al., 2010).

Both staff and clients deemed social activity to be an important indicator of success, even more strongly related to success in ACT than staying out of the hospital.

What We Know and What We Don't Know

Social integration is important to people with SMI and has been a focus of research on ACT (Angell, 2003; Calsyn et al., 1998; Krupa et al., 2005; Prince & Prince, 2002; Scheyett et al., 2010; Stull, et al., 2010). However, only Angell (2003) and Krupa et al. (2005) were able to elicit specific information regarding the manner in which ACT teams approached the problem of addressing social integration for their clients. Angell (2003) offered valuable information regarding several ACT team's facilitation of their client's social integration through the encouragement of interpersonal relationships between clients, between clients and non-mentally ill community volunteers, and through recreational outings. Krupa et al. (2005) suggested the use of client journals and the importance of the client/worker bond.

Several studies addressed the issues of stigma and community access for ACT clients (Prince & Prince, 2002; Scheyett et al., 2010). Forensic ACT teams were able to affect community change by the development of trusting community relationships, and in providing informal education regarding mental illness to individuals in the community (Scheyett et al., 2010). However, no methods were elicited regarding detailed or formalized interventions designed to overcome barriers to client social integration, or strategies used to help withdrawn clients interact with others in the community. In looking at perceived stigma and social integration, Prince and Prince (2002) found that their study participants believed that people with SMI were

devalued by society and that psychosocial functioning and perceived support was fundamental for community integration to occur. However, the manner in which ACT facilitated the development of strengths in these areas remained unknown.

Stein and Santos (1998) wrote that “a major goal of Assertive Community Treatment [ACT] is to help persons with mental disabilities become integrated into their communities as individuals” (p.5). It has been acknowledged that social involvement is a valued activity to both ACT workers and clients. Indeed, the ability to have social relationships was used by both workers and clients as a measure of client success on ACT (Stull et al., 2010). However, scarce insights have been elicited as to how ACT is supporting that activity. Especially telling is the assertion by Angell (2003) that the manner in which ACT is to achieve the goal of social integration is not embedded in the system, resulting in the use of unknown and informal methods devised by individual ACT workers.

People with SMI can and should be able to experience social integration according to their personal capacity and interest. When social integration is understood to be a process that unfolds over time (Ware et al., 2007), the manner in which it occurs will change as the person with SMI develops capacities, and will differ from person to person. For instance, Angell (2003) found that the majority of the clients interviewed preferred the company of other people with SMI due to the shared experience that enabled reciprocity, while other study participants desired to have social relationships outside of the context of shared mental health issues. Krupa et al. (2005) found that for some clients, developing relationships with workers was

the important first step in a process leading to greater capacities for community engagement.

Given that stigma, alienation and pervasive loneliness play a large and important role in the lives of people with SMI, research that examines the manner in which attempts at addressing these issues by ACT was warranted. This study was designed to gain a better knowledge of the ways in which ACT workers attempted to facilitate social integration, their perceptions and innovative suggestions for improvement, as well as the barriers they encountered, and also led to the discovery of clinically useful information. This information can be used to offer strategies for interventions and improvement. Successful strategies, once tested and shown to be effective could be formalized and embedded into ACT in the same way that peer counselors, nurse practitioners and other recovery oriented innovations have been added in order to improve the ACT model (Monroe-DeVita et al., 2011).

Chapter III

METHOD

The Research Approach

Interpretive description, an inductive research approach falling within the naturalistic paradigm (Thorne, Kirkham, & MacDonald-Eames, 1997; Thorne, Kirkham, & O'Flynn-Magee, 2004), was the method used to explore the experience of workers on ACT teams surrounding their efforts to facilitate social integration for their clients with SMI. This naturalistic method of inquiry recognizes the complexity of the human experience and realizes that truth is comprised of many realities (Polit & Beck, 2008). Benoliel (1984) suggested that, "truth ultimately rests on the direct experience of individuals" (p.5).

Although historically the research tradition of science has been mainly quantitative, that method was found to be insufficient in answering questions about phenomena that could not be measured. Nurse researchers increasingly borrowed from the social sciences and incorporated qualitative methods into the field of nursing research in order to gain the knowledge that can only be gleaned from the subjective life experience of people (Speziale & Carpenter, 2007).

The qualitative methods borrowed from the social sciences were primarily phenomenology from the field of philosophy, grounded theory from the field of sociology, and ethnography from the field of social anthropology (Mitchell & Cody,

1993; Thorne, 1991). Phenomenology seeks to explicate the essential structure of the human experience, grounded theory is based on the belief that broad human social processes determine individual human behavior, and ethnography seeks to observe and document human activity in the context of human universals (Thorne, 2008). Thorne et al. (1997) perceived the need for a method based on nursing's own epistemological foundations and put forth interpretive description as a systematic approach that yields knowledge consistent with the nursing discipline.

Interpretive description as a method of exploration evolved specifically to deal with the type of complex and experiential questions posed by researchers in the fields of clinical health practice (Thorne et al., 2004). In elucidating the type of research aim that interpretive description would be best suited for, Thorne et al. (2004) wrote, "Products of interpretive description ideally ought to have application potential, ... a clinician would find sense in them and they would therefore provide a backdrop for assessment, planning, and interventional strategies, in keeping with recognized nursing standards" (p.4).

In addition to elucidating patterns and interactions, interpretative description departs from generic descriptive methodology in that it goes beyond mere description (Thorne, 2008), is more interpretive than generic qualitative description, and includes a conceptual rendering of the data (Sandelowski, 2000). Interpretive description elucidates deeper contextual meanings and implications through inductive analysis and offers both theoretically and clinically useful material (Thorne et al., 2004). The researcher is challenged to not merely describe, but to look beyond the obvious and to

ask, “What is happening here? What are the dimensions of the concept? What variations exist? How are the phenomena similar or different from one another?” (Thorne, 2008, p.50).

The use of interpretive description to investigate the experience of workers on ACT teams as they attempt to facilitate social integration for their clients with SMI is a logical and fitting approach. The aim of this study was to provide deep insight, theoretical relevance, and at the same time address real problems and offer solutions for real people engaged in clinical health practice. In developing meaning and theory from the data acquired, insights from other theoretical sources are considered and may be supported (Thorne, 2008). However, we are reminded that any formally held theory cannot give full voice to the multiple realities to be uncovered in the research, and that the eventual theory will be grounded in and come forth from the phenomenon studied (Thorne, 2008).

Thorne (2008) listed seven ideas that represent the philosophical underpinnings of interpretive description. They are as follows, interpretive description studies:

- are conducted in as naturalistic a context as possible in a manner that is respectful of the comfort and ethical rights of all participants,
- explicitly attend to the value of subjective and experiential knowledge as one of the fundamental sources of clinical insight,
- capitalize on human commonalities as well as individual expressions of variance within a shared focus of interest,

- reflect issues that are not bounded by time and context, but attend carefully to the time and context within which the current expressions are enacted,
- acknowledge a socially “constructed” element to human experience that cannot be meaningfully separated from its essential nature,
- recognize that, in the world of human experience, “reality” involves multiple constructed realities that may well be contradictory, and
- acknowledge an inseparable relationship between the knower and the known, such that the inquirer and the “object” of that inquiry interact to influence one another (Thorne, 2008, p. 74).

In using the interpretive descriptive approach, it is not presumed that the researcher must start at a “blank slate” in terms of building upon previous work. It is considered naive to undertake a health related study without an understanding of the current state of knowledge in the field (Thorne et al., 1997). Prior empirical evidence in the field is not ignored or discarded, rather it is built upon and linkages are made.

The existing literature was reviewed for this study in order to determine what knowledge existed, and whether the question of interest had been sufficiently answered in a manner that was useful to the field of nursing. A gap in the literature was identified, with authors recommending that further research be done surrounding an area of research regarding how workers on ACT teams attempt to facilitate social interaction for their client’s with SMI (Angell, 2003; Calsyn et al., 1998; Stull et al., 2010). Several researchers expressed that although the concept of full community integration is consistent with the goals of ACT, the methods used to facilitate this aim

are not clinically integrated (Krupa et al., 2005) or embedded in ACT's design and delivery of service (Angell, 2003).

I am an Advanced Practice Psychiatric Mental Health Nurse with over twelve years of enjoyable and rewarding experience working in the community with people who have serious mental illnesses. I assisted individuals who lived in homeless shelters, in congregate housing, and alone in independent housing. I am saddened by what I perceive to be their exclusion from mainstream activities and their experience of social isolation. My experience has shown me that many people with mental illness desire social interaction and the experience of feeling connected to their community. I believe that people with mental illness can be assisted and supported to develop their personal strengths, enhance their social skills, and contribute to others if given the opportunity. I find the area of research regarding better ways to facilitate social integration for people with severe mental illness to be of great interest and importance.

Protection of Human Subjects

There were no foreseen risks to the study participants and there were no adverse reactions. The study participants were all adults employed as mental healthcare providers. Their participation was voluntary. Written informed consent was obtained prior to any interview. The informed consent was a process *consent*, a form of consent in which the participant could modify or withdraw from the consent they initially agreed to (Speziale & Carpenter, 2007) and could withdraw from the study at any time. In addition, I am a seasoned psychiatric nurse practitioner trained to recognize and deal with distress. Arrangements were made for referrals of participants to professional

counseling services, in the case that unforeseen distressing feelings arose during the interview process that required expert attention. These referrals were made available within the mental health agencies in which the study participants were employed or to an outside provider, at the participant's preference. The study participants were given my cell phone number and were asked to call if they experienced distress.

All recorded data were transcribed either by me or a transcriptionist who had obtained a certificate in the protection of human research participants and was approved by the Seton Hall Institutional Review Board. The transcribed data were stored on a memory device and kept in a secure, locked site in the researcher's home. The data received was de-identified prior to transcription. The electronic data base contained only de-identified data. Only the researcher and the supervising faculty member had access to the data. The informed consents and contact information were kept in a separate locked file in the researcher's home. The audio tapes will be deleted three years after the study's completion. The transcribed data will be stored for at least three years after the completion of the project.

Participants

The study participants consisted of 24 frontline workers on inter-disciplinary mental health community outreach teams based on the Assertive Community Treatment model, who had experience in attempting to facilitate social integration for the team's clients with SMI. The frontline workers were solicited from seven ACT teams operating out of three agencies reflecting different geographical locations and

two states within the Northeast metropolitan area. Sixteen participants were individually interviewed and eight participated in focus groups.

Three sampling approaches may play a role in interpretive description; they are convenience sampling, purposive sampling and theoretical sampling (Thorne, 2008). Purposive and theoretical sampling were used in this study. Purposive sampling is a technique in which individuals are asked to participate because they have had rich experience with the phenomena of interest. Considered especially valuable in the interpretive description approach for purposive sampling is the interviewing of individuals who not only have had experience with the phenomena of interest, but also have insight and thoughtfulness toward the phenomenon (Thorne et al., 1997; Thorne, 2008). Theoretical sampling adjusts to the needs of the study as it progresses, thus it allows the researcher to test the emerging theory from the data to see if one's hunches are correct, and to ensure maximal variation (Thorne, 2008). Thorne (2008) wrote:

An important element of theoretical sampling is the idea of maximal variation, in that, as hunches about patterns and themes begin to emerge from initial phases of data collection and analysis, you will need to search out specific "cases" in order to know whether what you are seeing so far is anomalous or an artifact of some unexplained characteristics of your current sample or study design (Thorne, 2008, pp.91-92).

All of the nurses on the ACT teams were invited to be study participants as their perspective is particularly relevant to the field of nursing. As the study progressed study participants were invited specifically to seek out different types of experience to

ensure maximal variation (Thorne et al., 1997; Thorne, 2008). For example, a peer counselor was asked to participate in order to understand the viewpoint of an individual who was both a provider and recipient of mental healthcare services. A nurse practitioner was invited to participate in order to glean his perspective as the psychiatric provider on an ACT team, and a program director that also saw clients was invited due to his global perspective.

Because ACT teams rely on interdisciplinary modes of decision making, in order to explore the perspective of a team while the interdisciplinary dynamics were visibly in operation, one agency was invited to participate in one of two focus groups each representing a different ACT team at that agency. There were no individual interviews undertaken with any ACT team workers at that agency. Only the team members that were willing participated in the focus groups. It was understood that the focus group might not include all team members and there was no coercion in that regard. The ACT team members at the agency in which focus groups were conducted retained the right to participate or not, as with all research participants.

Excluded from individual interviews were workers with less than three months experience, due to their lack of experience on ACT. However, all workers were included in the focus groups regardless of length of experience as it was the team's perspective, not individual experience that was being sought. Male and female workers were included, with no age restrictions.

Thorne (2008) endorsed the use of interviews with healthcare providers in order to further understand a problem that is associated with the consumers of the healthcare

provided, for instance, Thorne (2008) wrote, “I also think that the subset of informed, thoughtful, expert clinicians can become a wonderful resource for capturing the hard earned insights that each will have achieved and which may not have been shared collectively or documented in the literature” (p.85).

The participants in this study fit Thorne’s (2008) description of healthcare professionals with expertise on ACT teams, working on the frontlines with a challenging population. The participants offered valuable insights and observations that had never before been documented or shared.

In their discussion of data collection methods in qualitative research, Polit and Beck (2008) wrote that data saturation occurs “when themes and categories in the data become repetitive and redundant, such that no new information can be gleaned by further data collection” (p.71). Thorne (2008) posited that saturation and full depth of knowledge is unlikely to be achieved in the context of the complex healthcare environment and wrote, “In the disciplinary context of health research, the idea that one can claim that no new variation could emerge seems antithetical to the epistemological foundations of practice knowledge” (p. 98). She suggested that one should simply report findings from the data that has been explored with an understanding that additional and different experiences might yet be uncovered (Thorne, 2008).

Thorne (2008) suggested that, “interpretive description can be conducted on samples of almost any size” (p.94). She related that some studies might warrant larger numbers depending on the complexity of the issues studied. Although she suggested

that some research questions could be answered well using a small sample size, it would be dependent on the question asked and the type of information needed (Thorne, 2008).

This study consisted of a diverse group of 24 participants, 16 participants were individually interviewed and eight participated in one of two focus groups. The participants represented a wide variety of disciplines on the inter-disciplinary team. Although the team members shared many roles, each discipline also has its own unique role and perspective and it was important to this study that a wide variety of disciplines be represented. Nursing was well represented in this study as the perspectives of nurses are particularly relevant to a nursing research. Out of 24 participants, seven were nurses, and of the 16 interviews conducted, six were with nurses. Three team leaders (master level social workers) were individually interviewed; their leadership roles added a global perspective to the study. Two peer counselors participated in the study. Their perspective was particularly valuable to this research due to their unique insight as team workers who have a mental illness and at the same time, provide care for people with SMI. Three vocational specialists participated in this research and offered their important perspectives on the issues related to employment goals for people with SMI. Two substance abuse specialists offered their understanding of the barriers caused by the abuse of substances that is a frequent and ongoing problem that affects social integration for many of ACT's clients. Six workers with degrees in social work, counseling, or psychology who were intimately involved with the day to day life struggles and the social barriers of their ACT clients offered their perspectives on

facilitating social integration for their clients. A program director (a psychologist) of four ACT teams and with many years of experience added his understanding of the issues involved for administration, the workers, and the clients surrounding the experience of social integration.

The participants worked on seven ACT teams in two states. Each team served between 68-80 clients, and was staffed by seven to nine workers. The ACT teams interviewed represented teams that assisted clients in rural, suburban, and urban, low income neighborhoods, and served a diverse client population. The ACT teams served clients that lived with their families, in board and care facilities, independently, and in homeless shelters. All of the clients fit ACT's criteria for a diagnosis of SMI, and frequent psychiatric hospitalizations. In addition, some of the clients served were dually diagnosed with a substance abuse disorder.

Setting

In keeping with Thorne's (2008) statement that, "interpretive description studies commonly take place in the natural context to the extent possible, home visits or conducting interviews at offices or other convenient locations are quite common" (p.121), the interviews were held at the ACT office out of which the interviewed participant was employed. The focus groups were conducted at the office of each participating ACT team. Four ACT teams visited were located in busy, commercial suburban locations, and three ACT teams were located in different offices situated in the same building in a low income, urban location.

Gaining Access and Establishing Rapport

Participants were recruited from seven ACT teams operating out of three agencies reflecting different geographical locations within the Northeast metropolitan area. After contacting a program director at one of the agency's ACT teams, an invitation from that program director was given to present the study to a monthly joint meeting of the agency's ACT teams that was held at the conference room of a local library. The presentation took place on May 15th, 2012. Letters of solicitation were distributed to all of the workers at the meeting; a short presentation was made to an audience of ACT team workers, in which the goals of the study were explained. After the presentation, eleven eligible ACT team workers signed consent forms and provided contact information. Of those eleven, five participants were subsequently available to be interviewed and participated in the study.

Following contact with the director at a second agency, the proposed study was discussed and access to participants was requested. After that agency's institutional review board approved the research, I was invited to present the study to the agency's ACT teams. Letters of solicitation were put into the employee mailboxes one week prior to the presentations. The presentations took place on September 27th, 2012, to three separate ACT teams at their morning meetings, between the hours of 9:00 AM and 10:30 AM. After each presentation, interested and eligible participants signed consent forms and provided contact information. Eight interested workers signed consent forms and provided contact information. Three additional participants

subsequently volunteered to participate in the research study with a total of 11 participants from that agency's ACT teams interviewed.

A third agency director was contacted to solicit participants for two focus groups and an invitation was issued to present the study to two ACT teams at their morning meetings. Letters of solicitation were put into the mailboxes of all of the ACT team members one week prior to the presentations which were held on June 12th and June 13th, 2012. Eight members of one ACT team agreed to participate, signed consent forms, and provided contact information. Of those eight, five members subsequently participated in the focus group. Five members of the second focus group agreed to participate, signed consent forms, and provided contact information, and of those five; three members subsequently participated in the focus group.

The Question of Bias

Having worked as a nurse on ACT teams in the past, lent credence as I interacted with administration and the ACT teams. My prior working experience helped to establish rapport with the study participants. Because I understood the nature of their work from firsthand experience, I was able to design an interview guide that was sensitive to the particular questions for which answers were sought. As a nurse, with experience providing care on ACT teams in the past, I needed to remain vigilant in placing my own experience aside in order to be open to the experiences offered by study participants. I was careful to be aware of my own bias and to remain open to the viewpoints of the participants. Thorne et al. (1997) warned against individual bias and undisclosed biases that may be so integral to the field of nursing that we do not realize

its existence. Examples of such biases include that everyone deserves resources for healthcare or in this study's case, that individuals need social relationships.

Data Collection

In interpretive description it is suggested that collateral methods of data sources be used for triangulation in order to strengthen the analysis of the emerging data and give clues to the underlying attitudes that may be affecting the phenomena of interest (Thorne et al., 1997; Thorne, 2008). This study triangulated using the data collection methods of interview, focus groups, and a review of related documents. The individual interviews elicited the perspectives of individual frontline workers; the focus groups elicited the team perspectives from a group that works closely together, and the document review elicited material from an organizational standpoint.

Individual interviews began at one agency on June 18th, 2012 and continued until June 27th, 2012. Individual interviews began at another agency on October 9th, 2012, and continued until October 26th, 2012.

The study began with purposive sampling. As patterns and themes emerged from the data being analyzed, sampling became theoretical with several study participants sought who had different experiences than the participants previously interviewed. The questions asked were adjusted to follow new and unanticipated themes that emerged. After reviewing the signed informed consents, willing participants were individually interviewed for approximately 45-90 minutes, with the majority lasting roughly 60 minutes, utilizing a set of open ended questions aimed at answering the research questions in an unstructured interview. All interviews were

audio-taped and transcribed verbatim. The study participants were given the researchers cell phone number and asked to call if they felt that they had more information that they would like to add to their interview, alternatively, it was suggested to the study participants that they could email the additional information to the researcher. None of the participants elected to offer additional information after the interviews were concluded.

Thorne (2008) suggests that focus groups may be used successfully with particular questions and in the right context in order to add primary or collateral data and wrote, "Because the social dynamic of a focus group is the element that you are trying to generate, the method works best where your question is one with social dimensions to which each individual might contribute" (p.131). Two focus groups comprised of ACT team members that were not individually interviewed were used as collateral data supporting individual interviews. The nature of the ACT team is the blurring of roles, shared goals, and interdisciplinary planning and decision making (McAdam & Wright, 2005). As such, interviewing the team as a whole revealed team perspectives and the manner in which they functioned as an interdisciplinary unit.

Focus groups were conducted on June 29th, 2012 and on September 10th, 2012. After reviewing the signed informed consents the focus groups were conducted using open ended questions in an unstructured interview. Each focus group consisted of the members of an individual ACT team. One focus group consisted of five ACT team workers, and the other focus group consisted of three ACT team workers. The duration of the focus groups was for one hour each. They were audio taped and transcribed

verbatim by the researcher. Field notes were written immediately after the focus group sessions.

In interpretive description it has been suggested that documents be used as a collateral method of data (Thorne et al., 1997; Thorne, 2008). Blank treatment plans, service goals and job descriptions were requested and reviewed. The information gleaned from a review of the provided documents helped to uncover what was considered to be important to the individual organizations by what they included as client goals in their treatment plans and service goals. The job descriptions highlighted the staff positions that were considered essential to providing ACT services, and the duties that were expected of each discipline.

Data Analyses

This research used the techniques of concurrent data collection and constant comparative analyses. Thorne (2008) wrote that these techniques are commonly used in interpretive description, and described these collection and analytical methods:

These two ideas are fairly central to a way of studying phenomena in which you start with the assumption that aspects of the reality that you are studying are socially constructed and that to uncover knowledge about them you will compare and contrast different kinds of manifestations of them (Thorne, 2008, p.99).

The technique of concurrent data collection requires the researcher to gather data, engage with the data, and use that data to explore and develop conceptualizations before reentering the field to gather new data (Thorne, 2008). The findings from one or

several interviews may influence who one interviews or bring forward unanswered questions in need of further inquiry. Hutchinson (1999) described the method, "It requires that the researcher simultaneously collect, code, and analyze the data... The method is circular, allowing the researcher to change focus and pursue leads revealed by the ongoing data analysis" (p.194).

Constant comparison analysis was originally developed for the grounded theory methodology in sociology by Glaser and Strauss (2011). Thorne (2000) described this method as comparing one piece of data to other previously collected and related forms of data. What is similar and what is different is determined. The range of the possible relationships that may exist between pieces of data are examined in order to uncover patterns, themes, and to develop concepts about the phenomenon under investigation. Thorne (2008) wrote, " In many qualitative studies whose purpose it is to generate knowledge about common patterns and themes within human experience, this process continues with the comparison of each new interview or account until all have been compared with each other" (p.69). Hutchinson (1999) described the constant comparison method stating that, "While coding and analyzing the data, the researcher looks for patterns. By comparing similar incidents, the basic properties of a category or construct are defined; certain differences between incidents establish boundaries; relationships among categories are gradually clarified" (p.201).

The data sources were individual interviews, focus groups and document review. All transcriptions were read in their entirety several times and compared to the audio tape, before coding began. Wuest (2012) explained that the coding of data begins

by finding conceptual codes that describe the data. As the data is examined it is likely that some of the codes will occur on a more regular basis than others and these codes may be collapsed or grouped with other codes to develop categories of greater abstraction. As the data are examined using constant comparison method, re-coding is done as necessary to fit the emerging data. According to Germain (1999), categories are then grouped into clusters. The data are reviewed in an ongoing manner to search for themes, patterns and emergent concepts. Themes that differed significantly from other data were also being taken into account as they provided unique, contradictory and important perspectives, a recommended technique according to Germain, (1999). For example, in this study, the themes related to families, vocational employment, and the time pressure to transition client's to less intensive services provided contradictory but important perspectives to be considered.

Data analysis included the use of QSR NVivo 9 software. In keeping with Thorne's warning to not rely on coding overly small units of analysis, words or phrases (Thorne et al., 1997), transcripts were read in full and then compared against the audio tape for accuracy and the emotional tone of the participant. Detailed analytic memos were written after reading transcripts in which I sought to fully understand the meaning contained in the data. Reflective memos were written to become aware of my bias. In addition, coding was not done on words taken out of their context, rather as Thorne (2008) recommends, the participant's intent was explored for its deeper contextual meaning before coding began.

Interpretive description discourages a proscriptive reliance on coding, sorting and organizing, and gives greater importance to the researcher continuously using his or her intellectual capacities to explore the meaning of the data in an inductive inquiry (Thorne, 2004). In order to ensure inductive rather than deductive reasoning is taking place, the researcher should avoid “predetermined analytic strategies, such as content analysis, and overly small units of analysis, such as words or phrases” (Thorne et al., 1997, p.174). Line by line coding is cautioned against, as the microscopic focus may obscure the larger picture and suggests that the researcher “move in and out of detail ... asking repeatedly, what is happening here? ...the contextual nature of the data is respected and remains intact, and the researcher is guided to focus on, and engage in, the intellectual processes” (Thorne, 2004, p.7). In addition, coding prematurely is discouraged. A deep and thorough understanding of the data is needed before coding in order to maintain depth of understanding (Thorne, 2008).

Rigor

Guba (1981) suggested that the criteria needed in order to determine the trustworthiness of a study are the themes of truth value, applicability, consistency, and neutrality. In the naturalistic paradigm truth value has been called *credibility* (internal validity in the rationalistic paradigm) and refers to the notion that what has been reported accurately reflects the information and meaning provided by the study participants. Applicability is referred to as *transferability* (generalizability in the rationalistic paradigm) and denotes that enough rich description is available so that the reader will be able to determine whether the findings might be applicable to a different

population of interest. Consistency is referred to as *dependability* (reliability in the rationalistic paradigm) and refers to the study's contextual understanding and tracking of both the similarities and the differences in the data elicited. Neutrality is referred to as *confirmability* (objectivity in the rationalistic paradigm) and refers to the ability of the researcher to use methods that will, in as much as is possible, prevent the researcher's personal biases from influencing the findings (Guba, 1981; Lincoln & Guba, 1986).

Trustworthiness was enhanced by the use of triangulation. Sixteen individual interviews were conducted, two focus groups were conducted, and document review was undertaken. Transferability was strengthened by the use of rich, thick description, theoretical and purposive sampling, and the inclusion of study participants representing ACT teams in two states, serving rural, suburban and urban populations.

Dependability was enhanced by the use of analytic notes documenting insights and associated contexts. The analytic notes were kept in a separate data file. Analytic notes were added directly following the interviews or other data collection methods. The notes were dated and the time was recorded. Each note documented particular thoughts and questions of the day, with the type of actual research work being done documented for context. Patterns and emerging themes and any type of follow up were included. New insights into the data were documented and analytical thoughts tracked. The process of clarification regarding the research questions and the emerging data were documented, as well as unanswered questions and revelatory moments of insight.

Confirmability, or in the language advocated by Thorne (2008), *interpretive*

authority was enhanced by the use of an electronic reflective journal in order to support reflexivity, and to better understand the beliefs and personal feelings that the researcher held toward the phenomenon being explored, so that the reader can trust that what the findings reflect is outside of the researchers' own personal bias.

Regarding issues of credibility, Thorne et al. (2004) wrote that what is most important is that the conclusions contain clear articulation as to the manner in which the analytic process has transformed raw data into the presented findings. Indeed, the logical process used should be accessible to the reader. The manner in which conclusions were made from data should be clear, and the findings should be credible to a knowledgeable audience (Thorne et al., 1997; Thorne, 2000; Thorne et al., 2004).

Chapter IV

FINDINGS: WORKERS DESCRIBE ACT AND PROVIDE THEIR DEFINITION OF SOCIAL INTEGRATION FOR THEIR CLIENTS WITH SMI

In a discussion with a front line worker colleague regarding social integration for persons with SMI, he provided a story that demonstrates an apparent disconnect between a theoretical recovery goal and the actual difficulties inherent in the implementation of such goals. He stated, “I went to see my client today who lives in a nice suburban garden apartment. She urinated in a cup, opened the door and threw her urine out on the street; she does this all the time! How am I going to integrate her into the community?” This example is provided to illustrate the types of issues that the workers on an ACT team face daily.

Chapter four provides an introduction to the study’s findings, the ACT model as described by the workers, and the workers definitions of the concept of social integration for people with SMI.

The ACT Model as Described by the Workers

The clients. The workers described the clients served by ACT as people with SMI who were not successful in other more traditional office based services such as mental health clinics or partial hospitalizations. The clients did not do well in day treatment settings and tended to not like structured programs. They were described by a substance abuse specialist as, “the hard to reach client who has had multiple

hospitalizations, who struggles to get to their psychiatric appointments on time, and has difficulty getting their prescriptions”. A peer counselor in a focus group described ACT’s clients, “the population we deal with, you know, traditionally the ACT team, it’s the sickest of the sick, the worst of the worst, they have been in the system so long, they don’t know how to even get out of the system”. Another focus group member, a substance abuse specialist, described ACT as the last resort for treatment for certain individuals:

Most of our clients come from the state hospitals, if it’s not long term it’s been a revolving door. They have been in and out of hospitals a lot. They have been in a lot of agencies and programs and eventually they come around to ACT when everything else has failed.

Both focus groups and over half of the participants gave examples of social isolation as an issue for clients. Their lives lacked outside stimulation. A clinician described her clients’ daily lives and said, “I can definitely see them getting just bored with, just having so much time on their hands, you know, just watching the walls in some apartment or some house!”

The clients’ housing situations varied and were described by participants as living independently, living with families, living in group facilities, and as being homeless.

A focus on hospitalizations. The theme of recurrent, disruptive, and unwanted hospitalizations in the life experience of ACT’s clients was discussed by one of the ACT teams and the majority of the study participants. A major and ongoing focus of

ACT's workers is the provision of support so that their clients can maintain community life with as few hospitalizations as possible. In addition, because ACT is an intensive and expensive method of mental healthcare delivery, a reduction in costs in terms of hospitalization rates is anticipated (Bond et al., 2001). A director of several teams who tracked goal attainments statistically for several ACT teams described hospital reduction as a priority goal. He proudly explained that client hospitalizations on his teams were tracked over the last ten years and demonstrated a reduction on average of 50 percent from the year before the client was assigned to ACT to a year after they were assigned to ACT. During the second year with ACT, hospitalization rates decreased on average by 80 percent, thus showing that needed supports had been given by the ACT teams and the model was working.

The ACT teams provide extensive services in order to support the clients in the community and reduce the need for recurrent hospitalizations. The ACT offices are open Monday through Friday with typical business hours of nine to five. There are no weekend or evening hours on these teams. However, in order to support the clients in the community at all times, the teams provide a crises number that can be called 24 hours a day. Some of teams give out the work cell phone numbers of all of the workers so that the clients can contact any one of them if needed.

The morning meeting. In order for the interdisciplinary team to be aware of the concerns regarding all of the team's clients and to function as a unit, the teams meet every morning for about an hour. Client concerns are shared with the other members of the team and immediate tasks are assigned. Who will be seeing which clients each day

is determined. A nurse explained the importance of the morning meeting by saying, "At the morning meeting we discuss top issues for every one of our clients and then, as we go out in the field, we adjust to what is appropriate for what they need". Special attention is devoted to clients who are not doing well and a plan is devised. Treatment plans for each client are also discussed, as are medication issues and issues of substance abuse. A goal is to have all staff on the same page regarding the needs of each client on the team. All of the disciplines have equal input at the morning meeting. For instance, I was assured by several of the participants that the opinions of the peer counselor impacted on clinical decision making as much as the opinion of a worker with an advanced degree. As one of the nurses stated, "Yes, everyone from the peer specialist to the psychiatrist, everyone's opinion is validated". Soon after the morning meeting, the workers individually head out into the field to see clients.

The interdisciplinary team: Shared roles. While in the midst of data collection, it became clear that a better understanding of the nature of the interdisciplinary team was needed. Participants explained which aspects of their work on the team were shared by all disciplines, as well as what they did that was unique to their own discipline. A team leader explained that everyone on the team was given the basic training required to handle all of the types of situations that might arise when they visited the client in their home. For example, a social worker said that she would handle any situation from a substance abuse issue to a minor family crisis. If the situation were more complicated, such as if a serious family crises arose requiring the inclusion of additional child services, the worker that was present at the situation

would bring that information back to the team, share it at morning meeting, and the family specialist would be assigned to visit that family. For medical situations, the worker could call the psychiatrist, nurse practitioner, or nurse for their expertise. If the worker (of any discipline) decided that they needed to call 911 to hospitalize a client, they could make this decision on their own, and the team leader would be informed of the hospitalization by cell phone.

All of the disciplines visited the clients alone. The only time team members paired up was if a client was known to be psychiatrically de-compensating and possibly dangerous. In one case, the psychiatrist on a team was accompanied by a nurse on his visits because of a language barrier. In addition, all of the disciplines attempted to form therapeutic relationships with the clients. In some circumstances, clients were able to relate more effectively to particular workers on the team. A focus group member extolled the virtues of the interdisciplinary approach by saying:

One thing I like about ACT is that there is no caseload, if you have a caseload that means that you have a certain client assigned to you. So that means sometimes there's an irritation or resistance. So if somebody doesn't like you he won't see you. But on ACT, we have different people. We all go there and do the same things...somebody else can continue, so our job is to make sure we help our client reach their goal and objective.

All of the disciplines are involved with groups and activities. Often the group leader had expertise in the type of group or the content that the group focused on. For example, the substance abuse counselor ran the Mentally Ill Chemical Abusers (MICA)

group, and the RN ran the diabetes awareness group. However, there were times when the group or activity leader had no specific training in the particular group's focus. For instance, a nurse took it upon herself to be the activities person for the team by arranging tickets for theater and sporting events that were distributed to the clients and their children on a regular basis. Another nurse described an activity that she participated in by visiting the zoo with the clients and other workers on the interdisciplinary team. That same nurse also described taking a client on the bus and teaching him how to get to school.

There is a good deal of overlap in the services provided between the disciplines supporting identified goals for that client. For instance, one of the participants stated:

They want to reduce their smoking, that's something that is discussed with them by their psychiatrist. It's reinforced by the nurse, the social workers, the LPNs. So normally when someone goes out, it's noted in their chart that they want to reduce their nicotine. That's emphasized over and over, I think the repetition is helpful and it's something that we all do.

The interdisciplinary team: Roles unique to the discipline. Each discipline brings its unique skills to the team. For example, the nurse monitors medication and arranges for it to be delivered on time. RN's administer medication such as monthly or bi-monthly decanoate injections in the client's homes. Nurses provide medication education, check on medication adherence, and assist with hospitalizations. In addition to psychiatric symptoms the nurse may address co-morbidities such as giving insulin or arranging for outside medical attention. The relationship that the nurse develops with

the client becomes more than solely about psychiatric or medical symptoms. Caring relationships develop. One nurse stated that he was a nurse, but was also a “friend”.

Another nurse said:

I come in from the medical aspect and then I might go anywhere from there. It just depends on the relationship that I have with the client. It can go ... to we're talking about women's shoes, to guys. We're talking about different things. But it just goes, it varies. It starts off on a medication level and usually goes everywhere.

The clinician role is the role of the worker with a social work or psychology degree. They may spend a little more time talking with the clients about their feelings and helping them to process experiences. If a client is having an emotionally hard time he or she might come into the office specifically to see the clinician. A psychologist spoke about doing therapy with the clients. He described therapy as an ongoing experience, something that happened in every interaction with a client. He believed that traditional therapy could be overwhelming to ACT clients. He saw interaction with the team members and other clients in groups or activities as all opportunities for connection that could be in itself therapeutic:

We do non-traditional therapy. I do my best therapy in the car, while waiting at the Board of Social Services, while waiting at the doctor's office. Grab a basketball and go with someone and shoot hoops and talk and do that. So, a lot of times the group's the therapy, if it's not specifically group therapy, it might be cooking group. But, it's really so much more than cooking group.

In addition to general social work skills, the vocational specialist focuses on finding and supporting vocational and educational opportunities for the client, or linking the client to vocational training programs. Likewise, the family specialist provides social work services and at the same time will be called on to address serious family issues that other staff members cannot handle.

The peer counselor (or the mental health peer advocate, there are different titles in different states) has a special and important role on the team. Because the peer counselor has a history of a mental illness they function as a role model to the clients for recovery. One of the team leaders described the peer counselor as “more sensitive to the emotional changes” of the clients and thus better able than others to alert the team when the client was beginning to decompensate. The shared experience of mental illness engenders trust in the peer counselor’s clients. One peer counselor described her role and the client’s response to her:

What I do is home visits...I deliver medications to the consumers. We have a session between me and the consumer. We discuss their feelings...We always talk about trust. Because the consumers say that they trust me more because I am a peer counselor.

According to a review of documents listing job descriptions for the ACT teams interviewed, one state did not require peer counselors (or mental health peer advocates as they were called in that state) to be on the team. The team could have either a mental health advocate or a mental health *peer* advocate. The mental health advocate was not

required to have a history of mental illness, but otherwise performed the same supportive duties as the mental health peer advocate.

The majority of the teams were served both by a psychiatrist and a psychiatric nurse practitioner; some teams were served only by a psychiatrist. These team members served more than one team and were responsible for diagnosis, medication prescription, and medication management. They were available for medication adjustments if a client was doing poorly as reported by team members.

A team leader described her role as seeing clients in the field, but also supervising the day to day activities of the team, being responsible for administrative paper work, and making sure that each client gets the best services that he or she can.

A review of documents revealed that the job role descriptions as recounted by the workers are in accordance with the provided official job descriptions. The role of the nurse as described in the job description is predominantly as the provider of medical and psychiatric nursing services.

Defining Social Integration for People with SMI

In order to understand the study participant's answers to interview questions regarding social integration, it was important to first understand how the concept of "social integration for people with severe mental illness" was defined by the study participants. Their experience attempting to facilitate social integration for their clients would be largely related to their own understanding of the concept. The themes that emerged from the data regarding this research question were: overcoming stigma,

social interaction, independent and interdependent functioning, and doing what normal people do.

Overcoming stigma. Five study participants raised this issue and described overcoming stigma as necessary for the person with mental illness to believe that they had a place in society. A team leader and a nurse described stigma as internalized stigma, the negative feelings that a person with mental illness holds about themselves. A substance abuse specialist stated, “The person with SMI needs to overcome, as I stated first, the stigma that mental illness is bad, that mental illness is a crippling disability”. Other participants discussed the need for external stigma to be reduced in order for social integration to occur. A director explained that people in the community were frightened of people with mental illness. He said, “A lot of times people don’t really understand mental illness and besides, just that stigma I guess is a part of it...I think when someone says or does something unusual, it makes people back up out of fear”. A clinician also believed that pre-conceived notions about mental illness interfered with the community getting to know the ACT clients as individuals.

Social interaction. Both focus groups and a majority of the participants mentioned social interaction as a key component of social integration. One focus group and ten participants described social integration as a matter of their clients getting out into the community and interacting with others. Participation in enjoyable social activities was identified as a necessary component of social integration by six participants. A nurse suggested that “being socially interactive may not mean that they’ll go work for Citibank, but there are things that they can do in the community and

enjoy themselves". It was also important to several of the participants that the interactions be appropriate societal interactions. One of the participants explained that it was through social, purposeful, and productive behaviors that some of the effects of stigma could be avoided. If the attitudes of society toward the mentally ill would not change, it was important to help their clients be able to fit in.

The participants described social interaction for people with SMI in three ways: social interaction with peers (people with mental illness), social interaction with peers and with people who are not mentally ill, and social interaction of whichever type one finds most comfortable. Several of the participants described social interactions with other peers as fitting their criterion for social integration. Examples of this type of social interaction included examples of a group of peers going to a restaurant, taking a walk, going to the beach, and as one participant reported, "being in the community doing normal things that normal people do". Social relationships with people who were not mentally ill were not specifically excluded, but they were not mentioned in the examples these participants gave of social interaction. A participant directly addressed the issue of whether or not socializing with people who did not have a mental illness was necessary for social integration to occur. He answered, "I don't think it's necessary to have social integration with a population that is not mentally ill, but I do think it would be necessary to be able to generalize the skills that they learn into the general population".

Two participants felt that for social integration to occur it would specifically include social interaction with people who had a mental illness *and* with people who did not have a mental illness. A team leader noted:

It means being able to integrate with others regardless of the fact that you have a mental illness. Not allowing the fact that you have a diagnosis of a mental illness prevent you from being socially active with your peers that have a mental illness, as well as those individuals that do not have a mental illness.

A social worker objected to the labels that created boundaries between individuals. She described social integration as being able to socialize with peers, with family, and with people who are not mentally ill. Socialization would be based on enjoying a movie or a meal, what one had in common with the other, and not focused on mental illness.

Three participants believed that what was important in terms of social integration was the level of comfort with the social interaction that the client had.

There was no general consensus on whether it was necessary to have social interaction with people who were not mentally ill in order to have social integration. Because the clients served by ACT are among the most severely mentally ill living in the community, several participants suggested that the simple act of leaving the house for any type of socialization is a challenge for many of them. Therefore, socializing primarily with peers, if that is fulfilling, may be considered a valid step in the continuum of social integration. The findings of this study suggests that the types of social interaction needed for social integration to occur in clients served by ACT will be defined as enjoyable, appropriate, and comfortable social interaction with either

people who have a mental illness or with people who do not have a mental illness, or with both.

Independent and interdependent functioning. One focus group and half of the participants individually interviewed discussed their definition of social integration for people with SMI as including the capacity for independent functioning. Being able to do what is considered normative, getting needs met, having employment, gaining an education and joining clubs were all mentioned as part of social integration. One of the substance abuse specialists described his part in fostering social integration. He said “helping them to learn how to manage their daily affairs in reference to healthy living, to doing daily chores, going shopping, learning how to travel...we talk about how to advocate for oneself.” Other participants talked about developing the capabilities to be able to access and use resources. One nurse wanted his clients to develop, “the ability to travel to places or find the Social Security Office or any other facility that is available to them so that they can effectively carry on some of the basic functions of life”.

Independence was linked to interdependence; a psychologist suggested that, “To be able to be independent, you have to rely on other people”. Supportive relationships were encouraged. Several participants noted that the ability to communicate needs and access resources was essential.

Doing what normal people do. One focus group and four participants used the word “normal” in describing social integration. What they wanted for their clients was to be able to do the same things that “normal” people do in their everyday lives.

Participants mentioned the procurement of housing, the ability to work, to have friends, to have someone to take a walk in the park with. A participant summed it up well when she explained:

A lot of mentally ill patients when they come to us, they're usually in the hospital for a long time, or sometimes in prison. They're usually in some type of institutionalized situation or capacity. And their social integration back into society is them coming back into the community and trying to be as normal as they possibly can, to have the best life that they can live.

Social integration defined. According to the participants in this study “social integration for people with SMI” means enjoyable, appropriate, and comfortable social interaction with either people who have a mental illness *or* with people who do not have a mental illness, *or* with both. Social integration also entails overcoming stigma, enjoying community life, functioning independently, accessing resources, being housed, and living as normal and satisfying life to the greatest degree possible.

Chapter V

FINDINGS: DEVELOPING RELATIONSHIPS: ENGAGEMENT COMES FIRST

The participants in this study articulated how necessary it was to get “buy in” from the clients, as a first step in the process of facilitating social integration for clients on ACT. All of the participants emphasized the need to facilitate client engagement as the initial step towards active involvement with treatment goals and program activities. While a myriad of services designed to enhance social integration through the development of social skills and the promotion of independent and interdependent living are offered through ACT team services, the primary steps of engagement between the client and the ACT frontline worker is commonly accomplished when the client simply agrees to allow ACT workers to visit. The client may agree to accept the most basic of ACT services, such as medication delivery. As the clients and the workers become familiar with each other, relationships develop. These relationships promote continued engagement in working toward mutually agreed upon higher level treatment goals such as group attendance, community based activities, independent functioning, and vocational or educational pursuits. The relationship between the worker and the client is an essential component of engagement and this chapter discusses the workers’ experiences of initially engaging the ACT client and goes on to discuss the step after initial engagement, which is the

agreement where the relationship between worker and client is developed. As one of the workers succinctly said, "If you don't have the relationship, you will not have any kind of positive outcomes". A number of themes emerged that expressed the ways in which engagement occurred.

Engagement

Getting your foot in the door. ACT is a service that many clients experience as being invasive, and many are initially resistant to ACT's practice of frequent home visits. A nurse provided his insight into the process of engaging the client:

The first thing we have to do is build trust, so they need to get used to the team coming over. When you first meet someone new, they may not want to talk to you for an hour. But they have to get used to you coming over, right?

That's normal!

The participants offered reasons that engagement might be difficult. One ACT team leader that meets new referrals explained, "Especially if they're in the hospital, everything I say, they are going to agree to because they want to get out of the hospital". It is later that resistance to the team may ensue. In some situations receiving ACT services may be state mandated. Other clients have been referred by the criminal justice system and simply are resistant to seeing ACT workers at their door. Some clients believe that they can function independently and resent what appears to be authority figures involved in their lives.

An ACT director explained that historically one of his teams had a low census (clients can refuse ACT services and will be dropped after repeated failed attempts at

engagement). When he looked into this problem, he discovered that this team would send a worker to the home of a brand new referral (new client), who would begin the visit by telling the new client about all of the wonderfully comprehensive services that ACT could provide for them. The worker would then discuss the “end game”, or the long-term goals. He said that the vast majority of people were overwhelmed by that approach, and said things like, “No, thank you. Get lost! All I want you to do is come and deliver medications; I don’t want to go to groups. I don’t want to talk about things. I don’t know you. Go away!”

What many of the clients wanted was to have their medication delivered. He told that team:

If all they want to do is have you drop off medications, what’s wrong with that? Let’s start there. That’s the foot in the door. I guarantee that once you get to know them, and we see them on a daily basis, they’ll begin to trust us.

This participant said that once the team changed their tactic to “the foot in the door” approach, the team’s census came up to the expected number. It was not important to think about the “end game” or to expect quick results. What was important was to get in and plant seeds, trusting that eventually the goals for the client would be reached.

Engaging the client to accept medication in order to remain psychiatrically stable was described by a team leader as an important early step toward the facilitation of social integration. A team leader explained that for clients who were not initially receptive to ACT services, taking the client out for coffee helped her to get her “foot in the door”.

Meeting them where they're at. Both focus groups and half of the participants offered that the interaction they had with the clients was dependent on having an understanding of the individual interests and needs of that client. A nurse offered his advice on engaging a client and said, "I think that they are individuals and you have to deal with them from an individual point of view". One focus group member said:

Everything is individualized. It really depends on the client and how they're feeling too. I mean sometimes I can walk in and use humor to break the ice and it's okay, and other times you have to be serious. You got to figure out what's really going on and kind of stay on their level.

Several of the participants specifically termed this individualized way of dealing with clients as "meeting them where they're at". This can also be described as working with the client from the client's understanding of what they need and finding out what motivates them. Another participant echoed the same sentiment, but called it "you can't speak Russian to a Chinese", meaning you have to be sensitive to your client's ideas of what is important so that you can engage them. A team leader explained that she looked to find what goals the clients have for themselves. When the client was resistant to engagement she would keep trying to engage. She explained, "So, it's a matter of beating our head against the wall and continuing to go out and reach them and try to connect with them on *what they say they want to do* [emphasis added] or what goal they want to achieve".

Not being better than. It was important to several of the participants to dress in a manner that the client could relate to, to not dress up, and to not act like one was better than the client. A substance abuse specialist echoed the theme of “not being better than” when he said:

I believe we build trust factors with clients and *we do not, repeat, do not put ourselves above the client* [emphasis added] and the empathy, not the sympathy, but the empathy of [having] to try to have compassion and to have an open mind and not to judge, and helping them to understand that they have support networks in place such as the ACT team.

A peer counselor at one of the focus groups talked about her personal style of engagement. She said, “I joke around with them, too. I don't want them to feel like she's just this serious person coming in here. I try to make it fun for them. I might say something and they'll laugh”. Showing the client that the worker is comfortable with them, using humor, and being genuine goes a long way in engaging a client.

One of the nurses described going into the client's home and sitting down on the couch (physically being on an equal level), deliberately showing the client that he was in no hurry to leave, that he felt comfortable with the client, and unafraid. He added that he would tell a few jokes, and treat the client like he would a friend or family member. He stated simply, “My goal is for them to have one moment of positive experience”.

Traits needed by the worker to develop a trusting relationship. One focus group and nine participants discussed the importance of building a trusting relationship. In order to build a trusting relationship it was important to treat the clients with respect, to be genuine, to be consistent, and to be honest. If you said that you would meet a client at such a time, you needed to be there at that time. A nurse described the importance of reliability and honesty, “I’m gonna follow through with what I’m telling you. I’m not going to pull any punches. I’m not going to toy with you. With all people, but especially with this population you need to have consistency to have buy in”. One participant explained that you need to be honest and to genuinely care about the client’s well-being. He said:

You know, you have to respect them. And they’ll know from the word go. They’ll know when someone is trying to put a con on them. You can’t con them. And you have to be well-meaning, and they need to know exactly what you’re about.

A consistent attempt at engagement can make a difference. The resistant and wary new client usually begins to trust and depend on the ACT team members over time. The barrier of resistance is broken through by the developing relationships. One of the participants explained:

Because they’re used to being in some type of institution where someone is the authority, and when they see us they’re like, “Oh I’ve been State mandated by this, a judge has to tell me what to do”, and after talking to our staff and

the friendships that start to form, they get really relaxed and then they don't want to leave the ACT team.

The participant added that now if a worker misses a day, the client wants to know, "What happened, nobody came?"

The Relationship between the Client and the Worker

The client's ability to have social interaction is initially strengthened through relationships with the workers on ACT. The relationship between the worker and the client was discussed by both focus groups and all of the participants and emerged as an important theme. A focus group participant stated, "As a social worker, as a therapist, I believe most importantly in relationships. And I believe that relationships are the most important factor for change". The relationship that develops between the client and the worker is often the first step in learning the social skills needed to have social interaction with people other than family members.

ACT as a support system. Many clients have strong family support systems in place. However, many ACT clients do not have family support due to parental death, dysfunctional families, or it may be that the clients have burnt all bridges with their families. In addition, according to the participants, many of the clients served by ACT have no friends. ACT fills that void in the client's life. As one participant explained, "Our role becomes such that we do help our clients to reach out to the community and become their family and friends and support system". The ACT team is there for them when they need help in getting transportation to a doctor or finding a food bank. They are always a telephone call away, even if it's in the middle of the

night. The clients learn that there is someone there to listen to their problems. Another participant reported, "They're giving you their problems and they want someone to hear because most people don't. You know, people run away from problems. But we're here not to, and that's what they know, and that's what they count on".

Caring relationships. ACT serves to provide a safe place to learn how to develop and experience caring and trusting relationships. This experience may help the client to go on to develop caring relationships in the community. In explaining this process as she saw it, a social worker said:

And I think somehow the attachment that they are able to make with the staff...they can use the same experience on the outside world. And having the experience of a positive relationship, a non-judgmental relationship, helps them maybe attach and seek out different relationships on the outside.

It wasn't just the clients who received benefits from the relationships that developed between clients and staff. Several of the participants believed the relationships to be reciprocal with both parties benefiting. A participant who was an immigrant to this country described a special kind of understanding that she felt from her clients.

Back when I first started working, this is my first year working with the severely mentally ill, then I was so surprised at how understanding and accepting people they are. Sometimes it's difficult to get it (laughing) from the general population, but they just, they're accommodating. I speak with an

accent, nobody, you know; they just very politely ask where I'm from, but it doesn't affect, you know, just they're very appropriate, very polite.

The workers interviewed described very caring relationships. On several occasions the participants had tears in their eyes when they discussed a client who had died. One nurse described a client with SMI who developed cancer, learned to advocate for herself in her medical care, and subsequently passed away. She spoke very fondly of this woman and her struggles, and called her "my heart". A focus group member sadly explained that many of their clients were getting older, the team cared about them a great deal, and when their clients died, everyone was affected. Another participant described how he had diligently worked with one of his clients who had been very symptomatic, guarded, paranoid, quiet, and hard to reach. He engaged him in a special group and worked with him until he came out of his shell and became "incredibly friendly, nice, sociable", but he died young and unexpectedly of medical problems, and this participant still thought about him.

A nurse cared for an elderly ACT client who lived with his equally aged brother in the house they had grown up in. When these brothers went to make their wills, they cared so much for the nurse on the ACT team, they considered her family and wanted to leave her their house (of course, she said no).

A participant described one of his relationships with a client who had had a tragic family history. Most of the client's family had died in a car accident when he was a child (he was the only survivor of the accident), his only remaining family member was a brother who later committed suicide. The car accident had occurred

around Christmas, and so this client usually de-compensated around the holidays. The client was hyper-religious and also a prolific writer/poet. One holiday season the participant took it upon himself to collaborate with this client, adding music to the client's poetry. Together they created religiously themed songs and performed them with the worker strumming his guitar, and the client singing at the ACT Christmas party. That year the client did not have a psychiatric relapse.

The caring relationships that occur between clients and workers can help to foster the client's emergence from a state of emotional isolation, as the clients learn that it is possible to be known and valued by others for who they are. The workers also benefited from a sense of connection to their clients and the satisfaction of knowing that they had truly helped someone.

Boundaries. Going into the client's homes to deliver care, as opposed to meeting the client at a clinic is a hallmark of ACT and at least half of the participants discussed this in light of its meaning in relation to personal boundaries. A natural softening of boundaries can occur when you spend years visiting a particular client in their home, sitting on their couch, and meeting their families (if they have one). When I asked the participants about their relationships with clients, inevitably the discussion would turn to boundaries. It was as if the participants felt uncomfortable describing the close relationships that they had with the clients and wanted to make certain that I was not getting the wrong impression. A social worker illustrated the struggle to get to know her clients well and at the same time to define her boundaries:

Yes, you're in their homes and you see them on that level, but everyone has facets to them, you know. People are mothers, they're daughters... they're outgoing, they love to dance...they love to watch movies, they love to laugh. A lot of times you miss out on that because you are delivering a service...you have an intention; this person is not taking their meds. You want to focus on that today...but people are just eating and laughing and joking, and there's this side that's more humane than the other side where it's so strict and rigid.

Another participant described her need for boundaries. A peer counselor on a focus group explained that although she wore her "heart on her sleeve", she didn't cross any boundaries. At first she was affected by the close nature of her engagement with her clients, she said:

I remember when I first started working, I thought to myself: If I'm going to be dreaming about these people every night this is not going to work. After about two weeks it was like...you do what you have to do with them. You do the best you can with them every day, but you leave it here and you go home.

Another worker described more rigid boundaries. He said that trusting relations were essential but there also needed to be boundaries. When asked to explain, he said, "I'm not your personal friend. This is not a buddy system. We are not loan officers (clients often ask to borrow money)... We are the ones that render mental health services for a quality of life". A peer counselor received supervisory help from her team leader in setting boundaries because otherwise her clients would call her to talk five times a day. The client's home as a setting for worker and client interaction, in combination

with frequent contact over a long period of time, lends itself to deep and familiar relationships. At the same time, to be effective, the workers were cognizant of their roles as mental healthcare workers, and the importance of maintaining professional boundaries.

The ways in which relationships foster social integration. Trusting relationships allow for growth to occur. The client believes that what the worker suggests may be beneficial. For clients that don't feel safe to even leave their homes, a reassuring worker is there to guide them. A peer counselor from one of the focus groups described how she provides a feeling of safety to frightened clients as they venture into the community:

I'll hold their hands, I'll put my arm around them...I touch, I know a lot of people don't touch. But I'm not like that face hugging, that kind of thing. But I will always touch somebody's hand, I will hold hands, I will put my hand on their shoulder and I guide people on the back, you know.

Because many clients are self-conscious about their diagnosis and worry that other people will see that they're different, the worker needs to be encouraging in their relationship with the client. A peer counselor described how she talks to her clients in order to motivate them to go out of the house. She would tell them, "You look fine. You're acting fine. Nobody's going to see anything different. Come on, I'm with you, you're with me. We're doing this together".

A participant who is a nurse practitioner on a team developed trust in his relationships with his medication non-adherent clients by listening to them, working

with their preferences, and allowing them to have control as he prescribed their medications. Because he understood mental illness, he would accept (within reason) their crisis calls at three o'clock in the morning. So when he would reassure his clients that if they took medication their symptoms would become bearable, they were likely to listen.

Even when a client is psychotic, the relationship can break through the psychosis. One participant recounted the story of a client who was floridly psychotic and had relapsed on substances. The client was hallucinating and was up on a roof yelling, screaming, and carrying on. A huge scene ensued with the fire department and police surrounding the house and trying to talk him off of the roof. He yelled back and threatened "Don't anybody come up here or I'll jump!" After keeping the police and fireman at bay for at least a half an hour, an ACT worker with whom he had a close relationship drove up and yelled "What the hell are you doing? Get your butt down here!" The client suddenly behaved appropriately and responded "okay" and he came right down.

Similar to the findings of Stanhope & Matejkowski (2010) in their exploration of individual client-worker relationships on ACT, not all relationships between each worker and each client on ACT are as close as the relationships some of the participants in this study described. Clients have individual preferences for particular workers. The same is true for the workers. A nurse explained that just like everyone else in his life, he enjoyed certain clients more than others. All of the participants described their relationships with their clients as important. At the same time,

although they were friendly, the staff never crossed the boundaries of professionalism. These stories illustrate that professional, trusting, and caring relationships enable the work of facilitating social integration.

Chapter VI

FINDINGS: FACILITATING SOCIAL INTEGRATION

This chapter describes the methods used by ACT team workers to facilitate social integration for their clients. Five themes describe aspects of the process of social integration: overcoming stigma, social interaction, independent and interdependent functioning, and living a normal life.

Overcoming Stigma: External Stigma

According to the labeling theory (Scheff, 1963), one's personal identity is damaged once labeled as mentally ill. The labeled individual internalizes the role of mental illness based on society's expectations of mentally ill behavior learned since childhood and is locked into that role by society. The concept of external stigma was addressed as if it was something to be expected. The participants evidenced little hope that the level of stigma in the community towards people with SMI could change. Although sixteen participants discussed stigma as important, except for agency-wide community board efforts, none of the participants recalled any organized team-based efforts at affecting community stigma.

In answer to a question regarding the team's efforts to reduce stigma in the community, a participant answered, "I guess there is an underlying assumption that the community is not going to change and therefore, how can the clients fit in?" The

efforts by the participants at addressing stigma were primarily directed at teaching clients appropriate behaviors so that they would not stand out. A focus group member illustrated the manner in which she approached this issue, "So in order to integrate them it's about exposing them, getting them out, and teaching them appropriate behavior, so that they're not so easily identified as somebody with a mental illness". Further illustrating the emphasis on "fitting in", a team leader explained the importance of teaching appropriate hygiene and increasing the client's insight into their own behavior:

Being part of the community with a good quality of life is not always easy to maintain or to accomplish with our clients. Some parts of their stigma are actually their lack of insight. Their own selves when they're out in the community. So that's something else that we have to work on, even simple stuff like their ADL's and hygiene. They don't understand that people notice that. They don't look presentable in the community. So that doesn't help their own experience of stigma.

Educating people about mental illness. Although many of the participants believed that stigma was an important deterrent to social integration, when directly asked, none of the participants were able to describe organized efforts by their own ACT team to address negative attitudes toward people with SMI. Several participants spoke about personal efforts at educating people in the community about mental illness. For instance, one participant said that she informed others that people with mental illness are more likely to be the victims of crime than the perpetrators of a

crime. She added that she was, “constantly educating” the people around her. A peer counselor addressed the stigma that occurred among staff. Whenever the word “crazy” was used in describing a client, she corrected that worker and informed them that they were being unprofessional. Only one participant, a nurse, offered a detailed description of a specific instance of attempting to correct a person’s view on stigma, in the community. In this case it was not the client’s behavior that she thought needed changing, it was the reaction of a community member to an ACT client with obvious mental illness. The participant described a situation in which she was waiting in line to get coffee when she noticed a man that she knew to be a client on another ACT team in her agency:

And this guy...He wears a helmet and he's got a swastika on his arm and he's just really bizarre looking. And he comes into Starbucks to get some coffee.

And he goes out and stands at attention (she laughs) while he's drinking coffee...and I hear somebody whisper, “that's a real weirdo”. I just kind of looked at him and I go, “You know that guy?” I'm not afraid to speak out...

“You know, look at what he's doing, he just wants a coffee. Suppose he comes in and looks at you, yeah, and says you’re the weirdo!”

Overcoming Stigma: Internal Stigma

The effects of internalized stigma were described in the modified labeling theory (Link, 1987). The experience of external stigma and the internalization of stigma affect the self-esteem in people with SMI and cause these individuals to withdraw from social situations. A peer counselor illustrated the effects of mental

illness on the self-esteem of her clients by stating, “they were diagnosed with a mental illness, so for them, a person with a mental illness is not smart enough for anything... for work, or for school”. The workers attempt to teach their clients that having a mental illness does not preclude having a fulfilling life. The participants described their efforts to educate their clients about mental illness and to build self-esteem.

Educating clients about their illness. Nine of the participants discussed educating their clients about mental illness. The education took place during one to one discussions and in wellness groups. The understanding of mental illness as a debilitating disease needed to be re-framed for clients so that hope could be engendered and internal stigma reduced. In order to raise the awareness that mental illness is a disease that can be managed similarly to other illnesses, a focus group member described the attitude he imparted to his clients:

Yes, when I work with the clients I believe that the sky is the limit. You know, mental illness is like when you have diabetes, high cholesterol, high blood pressure, they are all part of sickness. So, you don't stop your life because of your sickness. You have to learn coping mechanisms so you can effectively work in the community. So that is our goal, give them awareness.

A nurse described the manner in which she re-framed mental illness. She said, “It's a concern, it's something that needs to be addressed. And once you address it, it will resolve. You know, solutions will be found”. A peer counselor educated her clients to not equate mental illness with “being crazy”, that being mentally ill was “not so

bad". She advised her clients that their "problem" could be taken care of with medication or therapy sessions. In this way she attempted to ease her client's sense of self as permanently damaged, or "crazy". Knowledge about mental illness helped to ease the effects of stigma. A more difficult problem was the serious damage to self-esteem brought forth by being diagnosed and labeled as severely mentally ill.

Building self-esteem. Fourteen participants spoke about the issue of self-esteem. Several participants described their clients as concerned that their mental illness was obvious to the world. A nurse described her clients as having an internal voice that told them they would not "fit in". This view was corroborated by a peer counselor when she described her own feelings after she was diagnosed with a mental illness:

Yeah, I used to go out into the street, and I used to walk with my head down like this (she puts her head down) because I didn't want people to look at my face. Because they probably would have thought that I was mentally, that I was crazy or something.

Another participant spoke eloquently about how the effect of having a mental illness on self-esteem caused his clients to withdraw from society:

They went through something similar and it didn't work (referring to an attempt at social integration). "I'm a bad risk. I'm mentally ill". And they talk themselves back into going to that dark room, closing the door, and, "I don't want to be a part of life anymore".

His team prepares clients for possible social failure, while at the same time providing encouragement. He explained:

We tell them, “yeah, okay, you might meet two or three people that want nothing to do with you, but you might meet five or six who want everything to do with you”. And they get mesmerized by that kind of statement because they've never had that opportunity before.

The trusting relationship between client and staff can help boost the client's self-esteem. A pilot phenomenological study found that their participants with SMI were able to sustain and enhance their self-esteem through social and interpersonal relationships (Frank & Davidson, 2012). A participant described the therapeutic value of her relationship with a client. She broke through the wall of her client's insecurities by providing her client with the experience of acceptance. In doing so she was able to see an aspect of the client that other people do not normally see. She said, “I think that's very therapeutic because it brings out what's inside, and that's what we're supposed to do. It's breaking down these walls and these insecurities, making people feel good about themselves”. A nurse used the supportive relationships that her clients had with the ACT team to help them overcome internal stigma and boost their low self-esteem. She gave an example of what she might say to a client, “Take a good look in the mirror at who you are and how we treat you versus how other people treat you. And internalize that! And then take it outside”.

The encouraging, supportive, and inclusive relationships between the ACT team and the clients were described in the following example by a nurse:

Well, “nobody loves me, everybody hates me, I’ll go eat worms”. That thought process is in their minds, they’re up against that. I think it’s really incumbent on us ACT workers, I think not only to get our guys to understand that, “you know what, everybody loves you, you don’t have to eat worms today, save your worms for another day. You know, come with us, we care, you are one of us, we’re one of you”.

Social Interaction

Social interaction was mentioned by seventeen participants as the key component of social integration. Social skills were developed in one to one relationships with the ACT workers and in groups and activities. A director of four teams hoped that what was learned through the therapeutic relationships would “be generalized to the outside world”.

Social skill development through one to one interaction with the team.

Workers role-played with their clients before going on job or housing interviews to teach social skills. Participants discussed providing advice on personal relationships to their clients that asked for guidance. Workers helped clients process their own emotional responses to social interactions. They went for walks with clients and took them out for coffee. They also helped them with their hygiene and appearance.

A nurse provided an example of his attempt to improve the social skills of a client, an older woman who continually cursed at all of the team members when they would come to visit. The client historically refused to accept her prescribed deconate injection when a nurse would visit. Meeting her where she was at, this nurse never

told her to stop cursing, did not comment on it, and one day he even chose to curse back (which she seemed to appreciate). He was the only nurse she would allow to administer her injections. At the point when he felt rapport had been established with the client, he addressed her non-stop cursing and said, "You do a lot of cursing. Do you find people respond differently when you curse? Because you know, you can use different language".

Social skill development and social interaction: Groups and activities. The primary method through which social interaction was facilitated by all of the ACT teams was through the provision of groups and activities. Although the terms *groups* and *activities* were used interchangeably by the participants, for the purpose of clarity, the term *groups* refers to office based programs, and the term *activities* refers to community based recreational or educational programs. Twenty one of the participants discussed groups as integral to facilitating social integration. When the clients were able and chose (they are not mandated) to attend groups and activities, several participants noted this to be a higher level of engagement and socialization than that achieved with the one to one relationship they had with their workers. It was hoped that attendance at the groups could offer clients a safe place to learn and practice social skills.

The ACT teams offered groups several times a week on a regular basis with an average attendance of two to seven clients depending on the group. All of the teams provided at least one monthly activity.

Office-based groups. According to one ACT director, the inclusion of groups to the agency's ACT teams began in 2006-2007 as an answer to the state's increased expectations for the amount of face to face hours between clients and workers. An ACT team leader in that same agency explained that currently it was educational, rather than recreational groups that were primarily encouraged. A team leader of an ACT team located in another state clarified that the inclusion of groups for that agency's ACT teams had begun sometime after 2008, and was a result of a directive to include evidence based practices by that state's ACT advisory board.

An ACT director explained that the clients benefited from the inclusion of groups by providing the clients with a safe environment in which to learn and practice social skills. Socializing within a group is considered by most workers to represent a step beyond the one to one engagement initially sought between the worker and the client. A participant provided an example of a client that had not yet developed the capacity to attend groups, although she was able to work with the participant on a one to one level:

There's, yes, one client who just had severe anxiety issues and when she does come in the office, for example, she never exhibits those behaviors at home or with her family, but when she comes here she would act out. She would make racial comments or get physical... I attempted to work with her at home individually and to process those feelings...the decision was made that after the incident happened the year before... she didn't have those behaviors at home, so maybe just exposing her again in a group would make a difference.

But it didn't, she decompensated, and digressed to the behaviors that she exhibited before.

Clients who had the capacity to attend groups, could learn appropriate social skills within that social microcosm that could potentially be generalized to the rest of the community. While in the group the client could safely test ideas, ways of being, and the ways in which to ask questions. The other group members might agree or disagree with what the client said in the group, and feedback would be provided by the client's peers. Another participant illustrated the beneficial psychosocial aspects of the group in the development of social skills:

You have a group of people together, you know. Once that comfort level is established in the group, there is really not a lot to fear. If someone is acting obnoxious in the group, other people in the group are going, "Hey! You know you are taking away my time!" They do this, but on the other side of that same coin... they'll go up to him after the group and say, "You know, it's all good".

Regardless of the identified goal of the group, it is the interpersonal experience that occurs between the group members that may be the most beneficial. To illustrate this point, a participant offered a typical conversation that might occur between cooking group members as they stirred spaghetti, "Hey, you know what? I ran into this problem yesterday...I didn't know what to do, I was so embarrassed, Hey John, has this ever happened to you?" The participant exclaimed, "and that's, that's the magic"!

According to a team leader, one of her main goals for groups is to, “bring them out of their houses and meet people”. Attending groups is an opportunity for social interaction. Several participants offered that the clients developed relationships with one another that continued outside of the group. A participant described the relationships that evolved from one of his groups as very supportive. When a group member was moved to a long term care facility for medical problems, the other group members phoned that client and later decided to visit him in the long-term care facility as a group activity.

Evidenced based programs such as Wellness Recovery Action Plan (WRAP) or Illness, Management, and Recovery (IMR) are offered by the teams. These programs are a type of group which follows a specific curriculum. Four participants explained that their team provided a WRAP group. WRAP is a widely utilized and disseminated peer-led program that teaches self-management of psychiatric symptoms and has shown to be effective at increasing hope and supporting overall recovery goals. It also teaches people with SMI to learn to recognize and use their social support networks (Cook et al., 2009). IMR was discussed by both focus groups and the team leader of an ACT team as being particularly helpful in teaching clients how to manage their symptoms. IMR is an evidenced based program that is designed to assist people with SMI to work with professionals, recognize support systems, and cope effectively with their own symptoms (Mueser et al., 2002). A participant described an IMR group in which the group members were asked to identify their support systems:

I did an IMR (illness management recovery) group this morning. We were talking about the supports...you have to know what your supports are and you have to identify why they're so important to you. And both my guys talked about friends as being supports, and family being supports, and understanding that supports are there to help you when you are doing well, as well as to catch you when you're not doing well.

One team offered a health and wellness program in which the first half was office based, in the second half the clients were given ten dollars and taken to a local Goodwill store so that they could purchase an item of clothing. Another participant described a team he designed. He called it the V.I.P. Program and clients who were thought to be capable of supporting their peers were individually selected by the participant and invited to attend the weekly group. Being a member of the V. I. P. group was considered an honor. The group members played chess, read the newspaper, and discussed current events. One ACT team offered a "Biggest Loser Group" that included weigh-ins combined with nutritional education and walking. The clients appreciated a group called "Herbs are us", and went out on their own afterward to look for herbs. An ACT team provided a weekly socialization group. The recovery group met every week and taught assertive skills and mindfulness. A Consumer Advisory Board met to discuss the needs of ACT clients and make suggestions to the teams; they also socialized with one another over pizza.

The groups are located at the ACT offices and meet at regularly scheduled times. Which groups are offered is at the discretion of the individual teams. They are

generally educational groups and cover a variety of topics (in addition to the groups previously mentioned) such as a mental illness and chemical abuse groups, vocational groups, woman's groups, transitional groups, recovery groups, and diabetes education groups. A review of the treatment plans provided by two of the three agency settings revealed that only one agency had groups and activities listed on its treatment plan.

Activities and community experience. The participants discussed community activities with more enthusiasm and energy than they did educational groups. These activities were an opportunity for new impressions for both the clients and the staff. The community outings were not described as the herding of a group of people with SMI by staff; instead these outings were described as shared recreational community experiences that were generally enjoyed by all involved.

Participation in community activities required a higher level of social functioning from the clients than office based groups. These activities took place in the general public and did not offer the safe, controlled environment of the ACT office. Only one story was offered that described a misadventure related to a community activity in which one of the clients involved was not yet ready for appropriate community engagement. It is included as it is noteworthy in its demonstration of the risks of premature community involvement. Three focus group members described a recent outing to a small community zoo:

We get some people to come out with us once in a while and it proved to be very inappropriate and difficult...most of them were good. One woman was incredibly, no matter what we did, inappropriate, screaming while there were

families that she hates children, and she's jealous of them, and they should all be killed!

The focus group members described their own shaken feelings about the event. While this outing was difficult for them, they said that they will try again. One focus group member pointed to her co-workers and said, "especially these two, they're thinking of ideas, what can we do with them, where can we take them?" A peer counselor wanted the team to provide new impressions for their clients so that there would be more to discuss on her visits with them than just medication and symptoms. A participant on another team also described the need for providing new experiences for the client when she said, "I think they should be exposed to other things and not just be able to look at the four walls".

One ACT team creatively blended educational groups with community activities. The team leader described a "Wal-Mart" outing. Once a month, the clients were given ten dollars to spend on anything they wanted at Wal-Mart. After shopping, they met together and waited for the others to finish while they socialized at a fast-food restaurant. That same ACT team also organized outings to the food bank, and a local farmer's market. All of these activities exposed the clients to community life, were socially interactive, and provided education regarding nutrition or budgeting. The team leader described a very well attended monthly activity to a beauty school:

When I first started, I wanted to promote grooming. I knew that if you get grooming from a school it's at a discounted price than say going to a

professional stylist...we became such good customers it helped the school so now everybody gets it for free.... It's a tax break, yeah. It's their donation to us. So over the years you're seeing how to talk to the stylist... how to appropriately communicate to them what you want, how to say thank you, everybody gets a tip...and we take them to eat afterward.

This regular activity provided an opportunity for the clients to interact with others (the beauty school students) who are not mentally ill and do work in the community. In addition, the clients socially interacted with one another and the ACT worker over lunch. At the same time it enhanced grooming and self-esteem. The team leader reported that the clients always complimented each other on their appearance after the haircuts and shaves. The beauty school needed models for their students, the clients needed their hair cut and styled, this was a reciprocal exchange of services. The students at the beauty school had an opportunity to interact closely and engage with people who have a mental illness on a monthly basis. The team leader described the clients as being socially appropriate when she said, "they do not cause any problems at all".

Community outings to see animals were a popular activity with ACT clients. A trip to the aquarium was described by a focus group as having provided an opportunity for stimulating discussions with the clients about the nature of freedom and independence verses dependence on others. The clients were asked, "Would you want to be an animal free out on your own, or taken care of, knowing that your needs are going to be met?" Both focus groups and three participants described trips to the

zoo. A focus group member felt that the clients had a special affinity for the animals. A nurse described a client who had never previously wanted to participate in a community activity. Because the client had expressed a love for animals the team planned a trip to the zoo. This client who normally would not leave his house attended the community outing to the zoo and enjoyed himself very much.

Activities involving food were very successful at drawing clients. One focus group and six participants discussed food as a motivating factor for clients to participate in activities or groups. All of the teams offered barbeques and picnics in the summer. The focus group members laughed and said that the clients appreciated the team leader's barbequing style. Like the rest of us, the clients enjoyed socializing over a nice meal. A team leader described her hopes for what the experience of attending a barbeque with other clients would provide, "invite them to a barbeque to show them what does it mean company, what does it mean not simply food in order to be full, but food which can be shared with other people".

Restaurant outings were considered to be among the most successful at bringing the clients out of their homes. Compared to typical educational groups that would draw from two to seven clients, the restaurant trips were described by the various participants as drawing from 10-20 clients. A nurse explained that most of the clients never have an opportunity to go to a restaurant unless on a community outing with the ACT team. He described the event and said, "It was a social event where they were treated with a lot of dignity and respect. So here they're in a restaurant, a nice restaurant. They get to eat and we treat them all the same and they enjoy that."

When asked how this experience might facilitate social integration, he answered, “By going out and seeing and having positive experiences in the community, that could facilitate them wanting to do more community things”.

One focus group and two individual participants described a popular community activity in which they took clients to a Chinese buffet restaurant. A team leader smiled when recalling the Chinese buffet as an activity that her clients had particularly enjoyed, and said:

Actually, you know what the most, yes, yes, (laughs), this is funny, the most successful groups are the ones where food is involved. Like where the purpose of the group is food itself. Nothing else, like we used to do when I first started, at least once a month they would go to a buffet. Like a Chinese buffet, yeah, loved that”.

She added, “We don’t do that anymore for financial reasons and also because we shifted the groups around to be more educational, therapeutic, and less recreational”.

Additional successful community outings were trips to a large metropolitan city, museums, theaters, and sports events (tickets were provided by an agency that aided people with disabilities). A water park trip and an amusement park trip had also been popular. Physical exercise trips included bowling trips and trips to the YMCA (again, no longer possible due to budgetary issues).

A peer counselor in the focus group described a group she ran as promoting fitness and community integration at the same time. She took the clients for walks in places that they would not be likely to go to on their own. They took walks together

in the parks and on the boardwalk. She also described a wellness group that ventured into the community, she said, “We go to fairs, pumpkin-picking parks...we went to the beach this year. And this is all based on getting them out in the community doing *normal things*, things that normal people do”.

A participant vividly described a holiday activity that involved food, people, nature, interaction, and how meaningful it could be:

Oh, I still remember a year you know, having a picnic. Fine, I’ll cook the hot dogs all day long. But they’re there in the park. It’s a gorgeous day. The lake’s right there. Some walk, you know, a trail. I mean it’s getting out of the city, it’s getting out of their apartments, and it’s getting out of the house...It doesn’t have to be fancy. I mean, the basic simple stuff really has an impact.

Some of the community activities were educational, but most were recreational in focus. They assisted the clients with positive community experiences, social interaction, and provided opportunities for fun. Participants believed that the recreational community activities were important because they provided clients with a pleasurable experience, in contrast to their otherwise often drab existence. This was further described as something special that the client looked forward to, and something the client could discuss with their workers later. These findings are in accordance with a review of the empirical research regarding the protective effects of positive life events on stress, and a review of qualitative data exploring the importance of pleasure and fun in the lives of people with SMI (Davidson, Shahar, Lawless, Sells & Tondora, 2006). The researchers found that pleasure, positive life

events, and play all prepare the person with SMI to actively engage in the process of recovery.

Independent and Interdependent Functioning

Treatment plans are written in which the worker and the client establish goals. One of the goals of ACT is graduation to less intensive services. In order to achieve this goal clients needed to learn to function independently. A focus group member described this important goal, “Even though we are there to support them, and help them, and advocate...We have the two sides of the coin there where we try to be very supportive, but at the same time we have to teach them independence too”.

Teaching, not doing for: Activities of daily living. Many of the clients enrolled in ACT arrive with few independent functioning skills. A focus group member provided an explanation for this phenomenon:

Some of our clients are used to a sheltered environment. Eighty percent of our clients came from a state hospital whereby they were given a confined environment, structure, you know. They don't teach them, what you say ADLs (activities of daily living). So when they leave they don't know anything. They come out a blank statement. So our job is to teach them those coping skills...they don't have those skills.

A method used by ACT workers to develop their clients functional skills is by “teaching, not doing” for their clients. A participant described his teams approach by explaining their underlying principle, “We do not try to do for people what they can do themselves. And we try to kind of build a frame around individuals to help them

learn how to do it themselves". An example was given in the way in which a worker might teach his or her client to make a doctor's appointment. They might ask the client, "What's the phone number...how do we find the phone number?" The worker would then take out a telephone book and give instructions on how to find a telephone number. The worker would explain what would happen next, "A secretary is going to answer the phone and you're gonna say, 'Hi, my name is, your name, and I'd like to make an appointment to see Dr. So and So'". The worker would continue this step by step process until the appointment is made. If the client already possesses these skills, this type of instruction might be experienced as demeaning, so alternatively the worker might just hand the client the phone and suggest that they make their own doctor's appointment.

The clients are taught to go food shopping. An example was given by the focus group in which the client was encouraged to approach the super market workers to ask questions on her own (something that she was very hesitant to do). The clients are accompanied and taught to negotiate social service agencies. A nurse described "teaching not doing for" in her attempt to teach a client to do their banking:

If I have to take someone to the bank, I'll walk in the bank with them, I won't do their work. I'll go with them up to the teller. I'll prompt them with cues of questions they need to know about the system and filling out the paper.

In this way the clients develop some of the activities of daily living needed for independent functioning. She added that with a follow-up visit to the bank, the client would know how to fill out their deposit slip on their own.

Vocational. One focus group and eleven participants discussed the focus on vocation as an important aspect of ACT's services. All of the ACT teams interviewed had a vocational specialist on the team. The vocational specialists were tasked with finding employment and educational opportunities for their clients, arranging for volunteer work, offering a vocational group, and making linkages to employment training programs.

For clients who were not yet capable of being gainfully employed, volunteer work was encouraged. A participant extolled the virtues of volunteering as a good intermediate step. Volunteering exposed clients to an environment in which they had to learn to work with other people. The clients learned new skills. For those with a limited work history, it would provide some work experience.

A team leader described a very successful volunteering experience. The team had a very isolated client who refused to attend any groups or activities. Since it was known that she loved animals, she was asked if she would be interested in doing volunteer work with animals. She agreed that she would. A local animal shelter with an existing volunteer program was contacted. The client enrolled in the program, went through orientation accompanied by the vocational specialist on the team and started walking the dogs and petting the cats at the shelter. The client loved this volunteer placement, and at the same time was providing a service to the animals and to the community. Other opportunities for volunteerism suggested by the participants were the library, organizations devoted to medical illnesses, and NAMI, an organization advocating for people with SMI.

A participant who was a director of several ACT teams explained that the vocational focus included three levels. They were competitive employment, non-competitive employment (volunteering, babysitting, working under the table), and educational training. This participant tracked his agency's ACT team's clients' rates of vocational involvement for the past five years and found those rates to be from the mid thirty to mid forty percent. These rates were among the highest in his state and almost doubled the national rate of fifteen to twenty percent for ACT clients' vocational involvement. He was asked to elaborate on what he believed to be the reason for his teams' success. He explained:

It's about the people... It's the staff. If you have a motivated vocational specialist and you have a team of people that buy into the vocational, everybody's ability to do something, then you can go places. In other words, if you have a team of people who, because it takes a team, you have a team of people who are constantly saying this person can't work, this person can't do anything; you're probably not going to go anywhere. Your rates are probably going to be pretty low. But, if you have a team that buys into it, and you have a leader on the team, meaning the vocational specialist who is a go getter, who has the people skills, who has the salesmanship, who can go out and shake the bushes and go that extra step, I think that's how we maintain those numbers.

The employed clients often worked part-time. Some of the jobs held by ACT clients were described: a greeter in a bulk supply store, working at a gas station, managing a beauty salon, one client was an engineer, another became a long distance trucker,

working in retail, working as a shoe salesman, a bouncer, another as a cashier and there are also clients enrolled in school. Many of the clients who were able to function at the level needed for work were considered success stories, and went on to graduate from ACT. Vocational goals are important to ACT, all of the documents provided by the ACT teams referred to vocational goals.

Identifying resources. Clients were assisted in identifying beneficial community resources. These resources included food banks, psychosocial centers, weekend activities, and self-help groups. Because many clients did not have home computers, one participant said that he brought lists of community events that he thought his clients might be interested in. In addition, several nurses located medical home visitation services for clients who would not leave their homes.

Strengthening social supports. The members of the ACT team worked to support client and family relationships in order to strengthen their client's social support systems. According to several of the participants, it was the client with a supportive family that had the greatest chance of recovery. One focus group and 11 participants discussed the effect of the family support system on the ACT team client. Many clients who were otherwise socially isolated interacted only with family members. Basic needs such as overseeing medication adherence, shopping, and taking clients to medical appointments were identified as being supported by family members. The clients were taught to recognize the value of positive family social support (when it was there) through WRAP and IMR groups.

A nurse discussed educating the families about the need for independent functioning, so that the clients could be given the opportunity to develop independent living skills such as shopping, using the telephone and making appointments. The participants engaged with family members as well as with the clients when they visited the home. One participant said, "It's a positive, (family support) and working together with the family to help the person stabilize is wonderful, too". When asked if he thought social integration was a possibility for his clients, one participant answered that it was possible, and it would take the team, the clients, and their families all working together to support recovery goals.

All of the documents reviewed referenced the family and support systems in relation to the client. Additionally, on the ACT teams in one of the states studied, according to the job description documents, family specialists were included as team members.

Living a Normal Life

One focus group and four participants used the word "normal" in describing their goals for their clients. A team leader described her team's no nonsense approach to encouraging their clients to live as normal and satisfying a life as possible despite their mental illness. She said:

We tell our folks all the time, "You know you're on the road to wellness and recovery, and it's an ongoing road that you're going to be traveling. But don't let the fact that you have a mental illness stop you from doing things because that does not normalize you nor does it de-normalize you... You know it's

just the same as a person having cancer. They typically are not going to let that stop them from doing things that they need to do. They have to go to work if it's necessary for them to go to work. So don't let that hinder you. You can make the most of your life, but you have to be the one to make it. And don't let the fact that you have a mental illness be an excuse not to do things, not to integrate yourself into the community, not to put yourself out there, not to make friends, not to go to church, not to not attempt to get a job, and not to come here to socialize with others".

The ACT team workers described their efforts at facilitating social integration by developing trusting relationships that fostered client self-esteem, and motivated the clients toward the higher level treatment goals of social interaction with peers at the office and in the community. Skills of independent functioning were taught, resources recognized, and support systems were strengthened. Volunteering and vocational pursuits were supported and encouraged.

Chapter VII

FINDINGS: BARRIERS TO SOCIAL INTEGRATION

This chapter describes the barriers to social integration faced by the clients and also by the ACT team workers in their attempts to facilitate social integration for their clients. The barriers experienced are presented under the following themes: symptoms of mental illness, over-coming stigma, social interaction and community involvement, barriers posed by low income urban environments, interdependent functioning: families as barriers, independent functioning: vocational barriers, and time pressure toward graduation/transition.

The Symptoms of Mental Illness

Both focus groups and all of the individual participants described the symptoms of SMI to be obstacles in attempting to facilitate all aspects of social integration for their clients. The illness was described as cyclical with exacerbation of symptoms and re-hospitalizations that impeded forward progress. Even though the workers remained focused on recovery goals, for some clients, those goals were elusive. The severity of their symptoms impacted their ability to engage in social interaction, decreased the client's motivation to work towards improved social skills through attending groups and activities, and impacted their ability to function independently. The client's bizarre behaviors and appearance also elicited stigma and affected community life. A team leader was asked if she thought that recovery and

social integration were reasonable goals for ACT clients. She replied that she did not think it was a reasonable goal for all of ACT's clients:

Because our clients are persistently mentally ill, and as much as we emphasize recovery is possible, but we see that it's a long and painful process. I mean, we've been around for three years and it's unfortunate, and it may sound cynical, but it is the reality that for some clients the expectation is low because you know, our clients are limited unfortunately. What is the limitation due to?

The mental illness is a big factor in it, and also the social environment.

Another participant provided an insightful illustration of the difficulties caused by SMI as it affected both the clients and workers, and their ability to engage around treatment goals:

On any particular given day you can have somebody smiling at you and giving you their life story and everything is wonderful. That same person the next day, if not that night, wants to tear up their room [and] can become quite dangerous and needs to go to the hospital... I know some clients who literally change every hour by hour and it's tough...It's tough for clinicians, it's tough for nurses and doctors...can you imagine how tough it is for them [the clients]? I mean their whole world is basically all this internal stimuli going on. They have ten voices in their heads telling them to do these things that you shouldn't. So, who am I to come in saying, you need to do this or that? That's just one more voice.

In order to address the issues of psychiatric instability, the nurses not only deliver medications and administer deconate injections, they also monitor medication adherence by checking the clients' pill boxes to determine if they are taking their medication as prescribed. Nurses educate their clients about the importance of medication adherence for psychiatric stability. A nurse spoke about the insight a client needed to maintain medication adherence, and saw medication adherence as a facilitating component of social integration, and non-adherence as a barrier. A client had been doing very well, worked as an engineer, and then decided to stop taking his medication. Soon afterward he de-compensated and was hospitalized. The nurse said:

I went up there [to the hospital] and I saw him and we had a long talk, and he [the client] said to me, "I know now, I understand that I'll have to be on medication for the rest of my life. But if that's what it takes to stay stable, I will".

When he returned from the hospital he was medication adherent, remained stable, and went back to college. The client graduated from ACT and was considered a success story (two other participants used the same client as an example of a success story). When I noted that the participant looked proud as he spoke about his client's success, he replied, "Oh yes! It's some achievement because a job like this, it could be frustrating. For instance, you work with somebody year after year and you see no more, no progress". All treatment and service plan documents provided by the

ACT teams included information on medication education, medication provision, and symptom management.

Overcoming Stigma

Both focus groups and 12 participants described stigma as a barrier to social integration. Four participants used the word “crazy” in describing the way in which people with SMI were viewed by the community. One participant said, “Right off the bat, from what they learned in life, stay away from that person, you know, they’re crazy...mental illness equates with craziness”. A peer counselor was visibly upset when she described the way that she felt when she heard the word crazy used by her co-workers, “They’re calling my clients’ crazy, that’s not professional. And you know, I have a diagnosis too, and that’s like saying, oh she’s crazy too”.

In a discussion on stigma’s impact on the acceptance of ACT clients at self-help groups such as Alcoholics Anonymous, a participant explained that it depended on the client’s level of obvious mental illness. A client could be welcomed and fit in well with others if his symptoms were less apparent. This participant explained:

And you have other people, who because of their mental illness, you see them walking down the street and you can tell that there’s something not right about this person...and although they will sometimes be embraced, I think our clients are experts at picking up on very subtle social cues that they, I’m sure they don’t even realize they’re picking up on. But they see that people look at them funny, or they [the clients] make these social faux pas that they don’t even understand that they did. And people move away from them.

The level of community acceptance was described by a team leader as varying dependent upon the location. Urban areas were more tolerant of people with obvious mental illness than were rural or suburban areas. The same behavior that would be tolerated in an urban area would prove to be grounds for arrest in a suburban neighborhood.

One focus group and three of the participants discussed internalized negative attitudes toward mental illness as a barrier to engaging clients in groups or activities with peers. One participant suggested that clients wrongly think of other people with SMI as if they had a developmental disability. He said, "they're worried that someone's going to be there drooling on themselves or something like that. So they're like, why do I want to come to group with a bunch of folks who are like that?" A participant suggested that some people with SMI distanced themselves from their peers due to their desire to not be identified with a stigmatized group. She explained:

Because, maybe being mentally ill for so long...they have issues with these labels...So who are you tied to? You're not tied to people who are attractive. You're not tied to people who are outgoing, people who are smart. You're not tied to that. It's more negative. And you're going to look at yourself because you're being told this by people who are professionals, that you're this way, so how can you feel great about yourself when you have been linked to so many things that are unattractive?

Social Interaction and Community Involvement

Both ACT workers and their clients experienced many barriers to the treatment goals of increased social interaction and community involvement.

Motivation. One focus group and 13 participants discussed the lack of motivation on the part of the client as an important barrier to social integration. Depression and the negative symptoms of schizophrenia influenced motivation. The lack of motivation was seen as a symptom of the mental illness that needed to be overcome in order for the client to leave his or her home to engage with others, and go out into the community. A nurse offered that “a large percentage” of her clients did not want to come out of the house. Many clients socialized primarily with family members. Another nurse added that there was no inner motivation to leave the house. To illustrate his point he gave the example of one of his clients “I was talking to a young lady. She needs to get out and do some exercising, but she stays home and sleeps. So you have to constantly try to motivate them to get out”.

A participant said that the level of motivation for socialization depended on the severity of the client’s symptoms. She provided an explanation as to why it could be so difficult for the worker to motivate clients with severe symptoms:

They just don’t feel the need. Their life as it is, at home in front of the TV, or doing whatever they want, *is what they want* [emphasis added]...There’s no frustration in “I would like to do this”, or “I should do that” that sometimes doesn’t even cross people’s minds. They’re just satisfied with what it is. And

so there is no discrepancy in what they want their life to be and how they live their life. That's very difficult!

Motivating clients to attend groups or activities has been a challenge for the workers. When a nurse was asked what ACT did to develop their client's social skills, she answered:

Once again, inviting them to our groups and different things that we do. If they're at home, there's not really much we can do to somebody who is totally depressed, and you know, except to keep talking to them, and maybe one day they seem like the medication's working, or something's working. But, there's nothing to really do to bring them into socialization if they don't want to be there.

While discussing groups and activities, a nurse offered that her team has had a great deal of difficulty in motivating their clients to attend the office based groups. Although they provided fare for transportation, would occasionally provide transportation, and used food as an incentive, she said "getting people to come on a regular basis has been a challenge". Even when clients did attend groups it might be difficult to engage the clients with one another unless the group leader worked to draw clients into social interaction. However, there have been successful groups. A team leader described a substance abuse specialist who had the "personality" that enabled him to develop strong relationships with the clients. He was able to motivate them to come to groups. If they did not come on their own he would pick the clients up at their homes.

A team leader and one participant believed that the closure of psychosocial clubs in their catchment areas were a barrier to social interaction for some of their clients. These are unstructured programs that appealed to clients who could not tolerate structured groups. ACT clients who had used and enjoyed these social clubs previously, were now seen “lying on a bench park or whatever, not doing anything”.

Substance abuse. One focus group and eleven participants discussed substance abuse as a major barrier to “appropriate” social interaction and to working towards other treatment goals. A team leader disclosed that they were seeing more severe substance abuse problems with their newer referrals. The combined effects of SMI and substance abuse effected psychiatric stability in the already fragile client. The substance abusing clients were difficult to engage, refused visits, or were under the influence of a substance during a visit by the team workers. In addition, they were more likely than the other clients to go missing or become homeless. They had difficulty managing their budget and their self-care diminished. They often refused to engage around services such as groups and activities. A nurse described a client who lacked the motivation to take his medication on his own, but did have the motivation to walk miles on the highway in order to purchase illicit substances. Although they tended to be more socially active than clients without substance abuse issues, their social interaction was maladaptive and inappropriate as they primarily socialized with other substance abusers around their shared substance use. When asked about social interaction and his substance abusing client, a nurse practitioner answered, “They have social relationships with other drug addicts, other people that they met in jail,

which is not always good, you know". Another nurse suggested that the clients with substance abuse issues had more social interaction than clients without substance abuse issues, but again, it was inappropriate and maladaptive socialization:

They have their cronies that they interact with. Yes, they do. Because I know a young man right now he's telling me that he is using drugs because of people who he is associating with. And he has this group and they meet. There was a Jamaican guy who is not on the team anymore, he uses marijuana *extensively* [emphasis added]. So being from Jamaica, I know some of their kinda lingo, you know, so I said to him, "Where do you go?" He said, "I go to The Marabingie House"...it's like their meeting place.

Groups designed to aid people who are mentally ill, chemical abusers (MICA) are offered by the substance abuse specialists. One substance abuse specialist said that they used incentives, such as free movie tickets to give to the clients who regularly attend. Another substance abuse specialist explained that many of his MICA clients were still in denial about their severe chemical dependency. All of the documents provided by the ACT teams addressed the issue of substance abuse.

Social anxiety. Members of both focus groups and nine participants offered social anxiety as a cause for the social isolation experienced by some of their clients. Social settings would increase anxiety levels leading to increased psychiatric symptoms. Several members of a focus group offered their opinion that staying home around familiar people produced a feeling of safety and security. Clients were concerned that if they were not in their safe and predictable environment, their

psychiatric symptoms would exacerbate and they would be hospitalized again. A participant offered the example of a client who rarely left her home, she said:

We have one client who doesn't leave her house, or leaves her house maybe once a month to shop for clothes...what she says is that her symptoms increase, that her hallucinations increase... You know; some people just have thoughts... In social settings their auditory hallucinations increase as well, being those critical voices or, you know, beating yourself up for the way they [the client] look, the way they talk, the way they present.

A focus group provided an example of a peer counselor taking a clean cut looking young male client out for coffee one Sunday morning. Initially comfortable, he became increasingly anxious as the coffee shop filled with patrons. The peer counselor said, "With each person that walked through the door, you could see his level of anxiety rise".

A team leader in a low income, urban neighborhood offered that there was a great deal of anxiety about coming out into the community. She told the story of a client, a large African American male who did not look obviously mentally ill, but could look intimidating. He went out of his home one day and was caught up in a police sweep and arrested. His family didn't know where he was for three days. Both he and his family are afraid for him to leave his house now.

Barriers Posed by Low Income Urban Environments

For the teams that served urban, low income neighborhoods, five participants saw the socioeconomic deprivation and negative social environment as a barrier to

social integration. These clients grew up in poverty without many positive influences. A team leader suggested that it was the life-long lack of intellectual stimulation in the client's social environment that negatively impacted on his or her ability to meet treatment goals. A participant described the challenges faced by the clients in their social environment:

Right off the bat, the environment that they live in is part of the construction of their lives. I mean it's where they're at. It's not that we have the option to take them to some farm or ranch where their entire conception of what life is might be a little different than what they grew up with...if I take them to a ranch or a farm, you know, the guy that sells drugs won't be there, the community that might have a gang living on that block won't be there.

Safety issues are part of their lives. A participant explained, "If our clients felt safe and felt like they could walk around their neighborhood, of course, the social interaction...I feel like it would open all kinds of opportunities".

Not all of ACT team clients were fortunate enough to have appropriate housing. Some were homeless; others lived in over-crowded and or substance abusing households. Access to appropriate housing was an important issue for a team leader when she said that the barrier with the greatest impact on social integration for her clients was the lack of available housing. All of the treatment and service plan documents provided by the ACT teams addressed housing.

Interdependent Functioning: Families as Barriers

Families can function as a major support system in the lives of people with SMI. However they can also be a detriment to medication adherence, self-esteem, and the client's development of independent functioning skills.

ACT clients benefit from family support. Even clients who are otherwise socially isolated do interact with family members. A participant praised the virtues of family support when he said, "I think the family relationships are the strongest ones. They have the best possible outcomes, because they do have the family support and family looks out for them, protects them." In discussing a client who successfully graduated from ACT, had married, and was furthering his education, a team leader acknowledged the value of family support when she said, "Fortunately, he has a supportive family and that makes all the difference you know". Although the value of family support was extolled, members of both focus groups and 14 participants discussed instances in which families could also be a barrier to social integration. They offered examples of the ways in which family members lacked understanding of the causes and treatment of mental illness. They also provided examples of the ways in which family members contributed to a client's low self-esteem and interfered with the treatment goals of independent function.

A participant provided an example illustrating a family member's use of cultural beliefs regarding mental illness to treat their mentally ill family member, with detrimental results:

Some families don't believe in mental issues... We have a client who came from Ghana and her Mom is not, doesn't believe, she believes that she's possessed by demons! So, she took her back to her homeland, and they performed some type of a priest, voodoo, and she [the client] was very traumatized by it.

A nurse practitioner explained that families often stood in the way of the client's adherence to medication regimes, thus jeopardizing their psychiatric stability. Due to their own experiences with psychiatric medication they might recommend that the client refuse to accept medication. To illustrate this point the nurse practitioner described this process:

Some families tend to want to help their loved ones, but they're in the way more than anything else, because they dictate what that person is going to do as far as getting better. And it's not always the right thing. And then there're those people that are just totally against treatment in the traditional sense, like going to a clinic. They may have had some experience with mental illness or HIV. And whatever their experience is they don't want their loved ones to go through that, so they say, "don't take that medication. It's not good for you". So that becomes a barrier... they [the clients] love their families, so they want to listen to them.

Two participants offered examples of families concerned more about the clients disability check adding to the household then the forward progress of the client. A nurse provided an example of a mother and son (the client) in an enmeshed

relationship. Mother and son both had psychiatric and substance abuse issues. The son wanted to pursue his dreams of leaving home and becoming a truck driver. The mother would tell her son that he was “stupid” in order to keep him from believing that he could live apart from her. The nurse explained:

His mother wanted him for his benefits only. And how else would you do that? Just keep him down, beat him down... He’s a big guy and he comes in like this little child. [He was] just totally beaten up. Not physically, but just mentally beaten, and he would come in and just sit here in that chair. And just “I don’t know what to do; I don’t know what to do”.

The participants described family members who were supportive of their mentally ill child, but had long given up hope that their child could learn to live independently. They “coddled” their mentally ill family member and provided for all of his or her needs. Even when the ACT team taught the client skills of independent functioning, those skills were not reinforced at home. A participant illustrated this point:

So, the parents who are actually involved, they’re somewhat, in our perspective, overly involved. They stayed so much involved in their lives that they do take care of every little thing, and that person really never learned to make a phone call, to schedule appointment, or deal with finances.

Clients who had been enabled by and dependent on others for most of their lives resisted the workers attempts at teaching independent living skills. A focus group member provided her insight into the families’ enabling behaviors, and their

resistance to support the team's efforts at developing the client's ability for independent functioning. She believed that the ACT client had become the identified patient in need of care-taking by their family many years ago. The family members became enablers, that is, they allowed their mentally ill family members to remain completely dependent by doing everything for them. She added that the enabling family members derived their own sense of fulfillment by becoming care-takers. She said:

So this person [the client] gets better, what are the family members going to do? You know, so it's the family member who should also be getting support and being taught... to support the individuals to reach their highest level of recovery and wellness, rather than keeping them sick so that they (the family members) have a purpose in life.

The team leader of an ACT team that served in urban, low income neighborhoods believed that there was little understanding among the families about mental illness. When asked if the family specialist was able to help in these situations she answered, "Sometimes it helps but not always, depends on the receptiveness of the family. We've seen it work and not work".

Independent Functioning: Vocational Barriers

Being employed is considered a normal component of life. It was a treatment goal for all of the ACT teams interviewed. According to several participants, ACT's over-seeing bodies in both states recommended that thirty percent of ACT clients be

engaged in vocational pursuits. The success of one agency's ACT teams (discussed in chapter three) in meeting the goals of vocational involvement for their clients notwithstanding, other ACT teams struggled in this area. One focus group and six participants discussed barriers related to vocational goals.

The client's disability benefits in relation to employment were a major concern to both clients and staff. Before a client can be engaged by the worker in vocational goals, the effect of employment on the client entitlements must be considered. If a client is stable and is able to procure full time employment, their disability benefits will be cut off. Mental illness is a cyclical disease, and it is possible that the client would quickly decompensate and be re-hospitalized. Once cut off from disability benefits, the task of getting those benefits reinstated is long and arduous, and it may not happen at all. A team leader said that this situation warranted a lot of consideration. The client could end up with nothing. However, clients can work part time without risk of losing their benefits, although the amount of their disability check will be reduced. Even though the client will have a higher income in the long run, many clients are unwilling to accept a cut in their benefits. A vocational specialist said that to avoid a reduction in their benefit check, she had been asked by clients if she could get them, "off the books jobs". This participant explained that this was a "big issue" in her work as a vocational specialist. When asked "Do you think if that wasn't an issue it would be easier for you?" She replied:

It would be so much easier. It would be so much easier because people will tell me "do you have any off the book jobs?" I don't have any off the book

jobs. So, you know...they just don't want that. They would rather not make the extra and just keep what they have because they've been living that way. They've already figured out how to live comfortably with that money. So, me coming out and saying, "okay, you're gonna lose some of it, but you're gonna gain more", they don't see how that works.

During one of the focus group sessions, the members let it be known that of all the disciplines, the vocational counselor had the most challenging job. It was obvious that the team felt pressured to achieve the thirty percent goal of vocation required by the state. The vocational specialist explained, "It's unrealistic, that the, some of the State people, it's unrealistic some of their demands on these individuals, pressuring them to work. You have to have a certain number to work, and I disagree with that". She added that she and her team would work as hard as they possibly could at encouraging their clients to work, but she also felt, as did the other members of the focus group, that it was an unrealistic goal with this population. She said, "They need to come and see these people, not just assume 'Oh, we can get this somehow'". The focus group members went on to discuss clients who were motivated to work and found employment, but the stresses of employment were such that several of them decompensated and required re-hospitalization. Several employed clients stopped taking their medications so that they could be more alert on the job, leading to their psychiatric de-compensation. Other clients were successful at employment, but these were the high functioning clients who were about to graduate

from ACT and the workers felt that the teams' efforts weren't really necessary. These clients had only needed some extra support.

These same concerns were echoed on other ACT teams. A vocational specialist on another team said that her clients had too many other obstacles in their lives to focus on vocational employment. In addition, she believed that the pressure of employment would be too great. She helped them by linking them to vocational programs, but only when they asked her to do so. She did not raise the topic of employment on her own. Her explanation was:

I don't push it because... all too often people are not too interested in that. People have so many things going on in different parts of their lives that they want to focus on before that. People are trying to get back their children. People are trying to find housing. People are trying to stay out of the hospital. They are trying to find the right medication... They're just trying to be stable in the community, period... They're worried about not being accepted. Because all of these problems, it's not going to have longevity on a job. You know when you're there and you're worried about people looking at you strange because you're mentally ill, because you already have this in your head that you're mentally ill and everybody else can see that you're mentally ill. So, it's so many other things to work on before that kind of pressure is placed on someone.

Regarding the issue of employment, a nurse suggested that more money, resources, and programs that provide employment for people with disabilities were needed in order to truly provide vocational service for ACT's clients.

Time Pressure toward Graduation/Transition

As described in chapter two, the original ACT teams were to be time unlimited in services to their clients. Theoretically a client could be followed by ACT for the duration of his or her lifetime. In order to prepare the ACT client for a more "normal" life, the goals of ACT have changed to include a transitional process or graduation from the program.

The time unlimited nature of ACT is one of the items on the DACTS scale, a tool designed to determine fidelity to the model (Teague et al., 1998). In 2007, Washington State funded ten new ACT teams and included changes to the model. One of those changes was the expectation that ACT clients would graduate from ACT services through a slow transition to a less intensive (and less expensive) model of mental health service delivery (WA-PACT Program Standards, 2007). The TMACT (Monroe-DeVita et al., 2011) a newer tool designed to determine fidelity to ACT, reflects some of these recent changes and does not include "time unlimited" as an item, but instead it has added an item to its scale for fidelity, labeled "graduation".

All of the ACT teams interviewed worked towards the transition to graduation for their clients. In one state, although graduation was a goal, there was little pressure by the state to do so until the team believed the client was ready. A team leader

discussed motivating her clients toward treatment goals, but at the same time was appreciative of being allowed the time to do so. She could negotiate goals with her clients without undue pressure. Her team could be patient when patience was called for. She said:

The beauty of ACT [is] we're not time oriented... we're not sensitive to time, having to do something in six months and then be discharged... We have the luxury of time to take as long as it needs to take.

The ACT teams located in other state did have time pressure. Their clients were informed that ACT was a time-limited program at their first meeting. From the start the workers and clients worked towards a transition to lower intensity services. A nurse offered that the expectation of the time period to transition out of ACT was from a year to a year and a half. A team leader voiced her opinion that when ACT was time-unlimited, the clients had become too dependent on ACT services, which had been a barrier to their development towards independent functioning. She believed the movement toward transitioning the clients out of ACT was, "a good thing". A nurse agreed that the extra pressure on the workers to transition their client more quickly helped them to stay focused on treatment goals. Another team leader said that through a step by step transition process, and with the help of the city government providing resources, they had been successful at transitioning clients previously incapable of functioning without full ACT treatment services, to a less intensive level of service. A different team leader found this time limited approach to be problematic in that it did not allow for enough time to adequately prepare some of

the most severely mentally ill clients for discharge. It was her opinion that the close nature of the relationships between the clients and the ACT team workers had changed. She said, "Before it was better because it was ACT team clients for a long time, because it was ACT team forever, so we were like part of the family".

In her view the nature of the relationships between the ACT workers and the clients had been altered with ACT becoming a transitional program. She also felt pressured to continually justify why very low functioning clients on her team had not transitioned out. Although the transition and graduation process was seen as facilitating social integration, the time pressure to speed the process of recovery in clients was seen as a barrier by this team leader. She believed that the limited time span to develop close and familial connections between the worker and client negatively impacted on their recovery process.

Chapter VIII

FINDINGS: WORKERS SUGGEST INNOVATIVE SOLUTIONS: CREATING PATHWAYS TO ENHANCE SOCIAL INTEGRATION

This chapter describes the suggestions and ideas that front line workers believed would enhance their ability to facilitate social interaction for their clients. Each participant was asked, “Do you have any ideas for ways that you would like to try to facilitate social integration for your clients if you could?” Their narrative answers to this question were analyzed and their ideas are presented under the themes of social interaction in a drop-in center, social interaction in the community, vocational and independent functioning, and housing.

Social Interaction in a Drop-In Center

Unlike the usual provision of mental healthcare, ACT provides the bulk of its services in the client’s home. Unless the clients come to the office for a group, outside of the structured group activity there is no place for them to casually socialize with other ACT clients. Participants offered their suggestions to enhance social integration by recommending a drop-in space located at the ACT office for ACT clients to gather for groups and socialization. One participant complained that her clients had nothing to do at their homes. She said, “There’s nowhere to go and nothing to do, just the same old smoking cigarettes”. The drop-in space could also serve as a meeting place for forays into the community. When groups were not in

progress, clients could socialize with one another, and play pool or board games. One participant suggested that the drop-in space be staffed by a “master facilitator”. This worker would be someone with expertise at drawing clients out and engaging them in socializing with each other. Three participants suggested hiring an activities specialist to organize the socialization program at the drop-in center and to organize community activities and trips.

The participants described the types of groups that they would offer. In addition to groups already offered, such as the MICA and vocational group, a variety of recreational and creative groups such as relaxation, yoga, and art and music workshops were suggested. A nurse suggested incorporating the creative arts into the educational groups already offered. He explained, “I know that there are music therapists out there that can give free music therapy... that could be incorporated into a wellness group”. A substance abuse specialist suggested inviting outside speakers to the MICA group in order to motivate the group members with their inspirational stories.

A nurse suggested that “Journey to Wellness” a peer-led program be invited into the drop-in center to lead groups. Two participants suggested asking the clients what types of groups they would like to attend, in essence having the clients design their own program. Another participant suggested forming an ACT peer support program.

Transportation was discussed by several participants. A peer counselor on a focus group serving rural ACT clients was particularly concerned that there would be

“reliable” transportation to and from the drop-in center. A participant in an urban location with mass transit suggested that the clients be provided with transportation at first, and then later, once engaged; they might be willing to travel on their own.

Social Interaction in the Community

The ACT teams studied provided monthly community outings. These outings were popular with the clients and better attended than the educational groups.

Thirteen participants suggested offering an enhanced program of community activities with a recommendation that their frequency be increased to at least once a week. A participant described the importance of frequent contact between the clients in order for them to be able to develop personal relationships with each other. She said “Something that’s consistent and frequent. I think that’s the key, it needs to be that you’re going to see this person next week and you can talk about certain things, and you can, you know, the conversations can continue”.

The community activities would provide an opportunity for ACT clients to interact with fellow peers around recreational activities on a regular basis. A participant suggested that the activity destinations be chosen by the group members. She said, “Take them to the current movies out there, take them bowling or golfing or whatever... basically what happens is that you sit them all down and you ask them, “Listen, you guys tell us what you want to do”.

Depending on the circumstances of the planned event, the community activities could take place in the day or in the evening. One focus group member suggested that the community activity group be tied to a social skills training group

held at the office. The activity group destination chosen would relate to whatever skills the clients were working on that week. The activities would be attended by clients and staff, as one participant said, "You can never forget the staff, you know, everybody is intertwined".

A team leader and a peer counselor both suggested that the team worker best suited to running the community activities group would be the peer counselor. A peer counselor felt that she was adept at motivating her clients to venture into the community and her ability would be enhanced if she had more interesting places to take them to. She said, "I think I have a pretty good rapport with most people, I can cajole most people to come out, I would like more places to cajole them to come to, you know, instead of just twenty minutes coffee". Another peer counselor suggested that the activities should take ACT clients to places that they had never had the opportunity to go to before.

The desire to provide new life experiences for ACT clients was echoed by eight participants. A peer counselor said, "I would be in that same mode of just expanding their horizons, getting them out... I would like to have a van where we could really just go pick everybody up and head out".

These were not suggested as regular weekly trips, but rather on a sporadic basis. One team leader said that many of ACT's clients had never been on a vacation. Influenced by her past social work experience in the foster care system, she suggested taking her clients on a vacation to Disney World. She and another participant also suggested a weekend camping trip as a more affordable vacation option. The

members of a focus group discussed a weekend beach trip. Focus group members and a team leader suggested trips to a major city in order to expose ACT clients to museums and other new experiences. Three participants suggested trips to a large amusement park.

Vocational and Independent Functioning

Three participants suggested activities that promoted social integration by providing for independent functioning through vocational opportunities. Several participants believed that there were not enough employment opportunities that were suitable for their clients. A participant suggested a supportive vocational program geared to the needs of a population with SMI that had linkages to jobs that the clients would feel comfortable in doing and enjoy, so that the client could maintain an interest in their vocational pursuits. She believed that her clients would be motivated to work if they felt secure in a supportive workplace sensitive to their needs. Another participant described the need to promote work that suited the strengths and talents of the individual client. She said, "We have a client that is not gainfully employed but he is a very, very skilled artist, and I would love to have money for him to expand his ideas, do something with his art, so a job is the biggest thing".

Two participants had been impressed by a television program in which they learned about community gardens that were developed in another urban, low income neighborhood. These participants suggested using the roof of the ACT office to create the ACT community garden. Clients could be employed to work the garden and the community could also become involved, thus facilitating community and client social

interaction. When the produce was grown the clients could sell it to members of the community. The participant suggested that it would be beneficial to clients that could learn about gardening and nutrition and, “you know the pride, the pride that comes along with working and earning money”.

A nurse suggested a transitional residential program that would serve ACT clients recently discharged from the hospital. For several months the client would live at the transitional residence and learn the needed skills of independent living. Although an interesting idea, she admitted that it would change the structure of ACT by making it a transitional housing program, which it is currently not.

Housing

Three participant’s suggestions had to do with housing. One participant described the lack of decent housing as the most important barrier toward social integration. The clients who were homeless lacked the stability for participation in higher treatment goals. The participants also found it difficult to socially integrate their clients into communities in which the clients felt unsafe. Two participants suggested the development of an aesthetically pleasing, supportive, community housing complex for ACT clients in a safe neighborhood. Again, this would change the nature of ACT and transform it into a housing provider for people with mental illness, but several participants saw the need for this shift. A participant described her feelings about the board and care homes that some of her clients lived in, and the effects on their mental health. She said, “It’s like nothings there. It’s terrible. I just think if they had better living conditions they would be in a better state of mind”.

Chapter IX

DISCUSSION and CONCLUSIONS

Summary of the Study

The research findings reported here are the result of an in-depth inquiry with frontline ACT team workers who described the interventions they found to be successful in their attempts to facilitate social integration for the clients with SMI. Participant workers also explained the barriers they faced in this process within the context of real life situations encountered in their work with clients. The participants defined the concept of social integration for people with SMI based on their experiences and insight, and they offered suggestions on the ways in which social integration might be improved for clients served by ACT.

The following discussion examines the key findings of this study in relation to relevant literature. The themes of understanding social integration as a concept, engagement and the worker/client relationship, facilitating social integration through groups and activities, facilitating social integration through independent /interdependent functioning, housing, and the workers' suggestions for ways to enhance social integration are discussed and interpreted in light of current literature and practice.

Meaning/Interpretation of Findings: Understanding Social Integration as a Concept

The workers were initially asked to explain how they understood the concept of social integration. The majority of the participants described social integration as experiencing enjoyable social and community interaction; however, the participants also included descriptions of additional criteria that provided further depth and breadth to the definition. A more comprehensive definition of social integration for people with SMI was synthesized from participant responses and is expressed as, “An enjoyable, appropriate and comfortable social interaction with either people who have a mental illness *or* with people who do not have a mental illness, *or* with both. Social integration also entails overcoming stigma, enjoying community life, functioning independently while recognizing support systems, being housed, and living a normal and satisfying life to the greatest degree possible”.

This definition suggests that socializing with peers is sufficient in fulfilling the requirements for social integration. Other studies found in the literature require that people with SMI have social relationships with peers *and* with people without mental illness for social integration to have occurred. In a qualitative study in which people with SMI were interviewed in order to discover a new definition for social integration, Ware et al. (2007) described the type of social interaction needed for social integration to occur and wrote, “They include persons without psychiatric disabilities who are outside the mental health system as well as those with disabilities”(p.471). In a study on the effects of stigma on community integration, Prince and Prince (2002) separated

community integration into the constructs of physical integration and social integration. The construct of social integration was defined as social interaction with non-mentally ill neighbors. Thus, relationships with peers were rejected as a valid measure of social integration.

The definition provided by the ACT workers was broader than the definition by Ware et al(2007) and Prince and Prince (2002) in that it included social interaction with either peers or with people who are not mentally ill or with both. It may be that for the population served by ACT, which was described as having severe psychiatric symptoms that impacted on their ability and desire to socialize, the capacity to enjoy social interaction is in itself an achievement, and is on the continuum described by Ware et al. (2007) when they wrote that social integration occurred over time as capacities developed. It may also be true that the choice to socialize in the community with peers may be due to the level of comfort that comes from being with others with a shared understanding of the experience of living with mental illness (Angell, 2003).

Meaning/Interpretation of Findings: Engagement and the Worker/Client

Relationship

The participants described engagement as a slow process that required “buy in” from the client. The initial step of engagement took place when the client simply agreed to allow the ACT team to visit and deliver medications. To be able to engage with the client required a slow and individualized approach with respect for the client’s personal interests, expressed needs, and goals. These findings support the findings of a qualitative study using philosophical hermeneutics, in which Wright, Callaghan and

Bartlett (2011) found that nurses on an ACT team in the United Kingdom achieved engagement with their clients through their ability to understand their clients as individuals in the context of their lives. The importance of a slow and individualized approach to client engagement is also consistent with the findings of a mixed methods study by Killaspy et al. (2009) investigating the reason for mental health consumers' preference for ACT team service over another model of mental healthcare delivery. In that study, the ACT workers' method of engagement had been described in part as having a "non-confrontational style, slowly increasing the amount of contact over time, and making the client's interests a central focus"(p.535).

This study found that through time, trusting one to one relationships developed between the workers and the clients thus enabling the client to emerge from a state of social isolation. For the clients, the relationships that developed between the client and the worker was often the first step in learning the social skills needed to have social interaction with people other than family members. It was in the company of the ACT worker that the client learned to venture into the community, shop for food, pay bills, and go to the bank. The client and worker took walks in the community, and went to the coffee shop together. The majority of the participants believed that it was through the trusting, supportive relationships they had developed with their clients, that they were able to motivate them towards selecting and achieving higher level treatment goals. This is consistent with the findings of Krupa et al. (2005) who conducted a participatory research study investigating the perceptions of ACT clients in relation to the ways in which ACT fostered their community adjustment and found that the clients

believed that it was the trusting relationships that developed between ACT workers and themselves that were crucial to preventing social isolation and in fostering community adjustment.

Although the participants provided poignant examples of the emotional and connected relationships they had with their clients, and the participants believed that trusting worker and client relationships provided the impetus for the most positive client outcomes, there are only a few empirical research studies on the value of these relationships in comparison to the abundance of research on the structure of the ACT model. A mixed methods study by Stanhope and Matejkowski (2010) with both clients and workers as study subjects, researched the relationships between the workers and clients of ACT. They found that it was through the trusting and caring individual relationships that developed between the ACT worker and the client that care was enhanced. Several qualitative studies found that receivers of ACT services formed trusting relationships with their ACT workers over time, and it was these relationships that fostered the clients' acceptance of services that led to higher level recovery goals (Chinman, Allende, Bailey, Maust & Davidson, 1999; Leiphart & Barnes, 2005). This research supports these findings. In addition, this research adds to the literature by also identifying the behaviors that participants believed to be conducive to developing trusting relationships with the client. The behaviors were: having a respectful attitude, meeting them where they were at, being consistent, being reliable, being available, treating the client as an equal, and having a genuine and palpable concern for the well-being of the client.

Although the participants believed that the relationship between the client and worker was considered to be very important in achieving client outcomes, the treatment plans reviewed do not reflect the importance of the client and worker bond. A review of the treatment and service goal documents from the research settings reflects the goal of helping the client to strengthen existing familial and social relationships, but nowhere is there an identified goal of developing the trusting interactive relationship between the worker and the client as has been described in this study and as has been found in the literature to be very important to achieving the best client outcomes (Chinman et al., 1999; Henry & Lucca, 2004; Leiphart & Barnes, 2005).

A major barrier expressed by the study participants in their attempts to facilitate social integration for people with SMI was lack of motivation in their clients due to what the participants believed to be the negative symptoms that accompanied schizophrenia or depression. Deegan, (1997) a well-known speaker, writer, and leader in the recovery movement, who is also a woman with SMI, described the lack of motivation that she had initially experienced after her diagnosis with a severe mental illness. She wrote that her lack of motivation had been attributed to negative symptoms. She believed that it was not the psychiatric illness that had caused her lack of motivation, but rather, the hopelessness that came from receiving a diagnosis associated with a disease that foretold of a dire life outcome. She suggested that the antidote to the negative symptoms and lack of motivation seen in people with SMI was the feeling of empowerment, and that feeling came in part from working with clinicians

who had the capacity to see the value in each of their clients, and the ability to love them.

Meaning/Interpretation of Findings: Facilitating Social Integration through Groups and Activities

All of the participants in this study described their attempts at fostering social integration by providing opportunities for social interaction through weekly groups and monthly community trips. The importance of offering educational groups that target social functioning and illness management such as WRAP (Cook et al., 2009) and IMR (Mueser et al., 2002) was supported in a retrospective study by de Haan, Linszen, Lenior, Doderlein de Win, and Gorsira (2003) in which they found that delayed educational psychosocial interventions targeted at improving social functioning, illness management, and self-esteem were better predictors of negative symptoms (lack of motivation, apathy) at a six year outcome, then was delayed psychopharmacology treatment.

ACT also offered a variety of other educational groups, such as substance abuse groups and health related groups such as diabetes and weight management groups. Groups offered the clients a safe place to learn and practice social skills and gain feedback from their peers in a controlled environment. Whatever the identified focus of the group the underlying function of the group was to provide opportunities for social interaction between the clients. This is consistent with a grounded theory study by Angell (2003), in which clients served by ACT were interviewed regarding the ways in which ACT developed social relationships. That study found that proximity to peers as

well as a shared experience with SMI served to set the stage for relationships to develop. The ACT teams studied in Angell's study also offered what was described as "engineered" socialization opportunities, in which they introduced clients that they believed to be compatible, and provided resources so that the clients could go out together and share a social activity. The ACT teams participating in this current study did not offer that intervention.

Participants believed that recreational community activities were important because they provided clients with enjoyable experiences to look forward to, in contrast to what participants have described as an often drab existence. These findings support the results of a review of the empirical research regarding the protective effects of positive life events on stress, in combination with a review of qualitative data exploring the importance of pleasure and fun in the lives of people with SMI (Davidson et al., 2006). In that study the researchers found that pleasure, positive life events, and play all prepare the person with SMI to actively engage in the process of recovery by reminding the person with SMI that life still offers the possibility of enjoyable experiences.

Community activities offered the clients an opportunity to spend time with peers and develop relationships. The clients and workers shared meals at restaurants, attended picnics and barbeques, and took walks in the park. Although these were not considered by ACT to be educational groups, in the company of peers and workers, the clients learned that they could enjoy community life. The community outings were not described by the participants as a herding a group of mentally ill people to a

destination, but rather they were described by the participants as social experiences that were enjoyed by both clients and staff together.

The participants in this study believed that providing clients with opportunities for enjoyable, social and interpersonal relationships was of paramount importance in the process of facilitating social integration for ACT clients. This finding is supported by a recent phenomenological study by Frank and Davidson (2012) in which they explored the meaning of self-esteem for people with SMI. Not only did that study find that for people with SMI, engagement in interpersonal relationships raised self-esteem, the study also found that for some people with SMI, social and interpersonal relationships equates with social integration.

The ACT model has been criticized for not fostering social relationships for their clients (Stull et al., 2010). Although the participants of this study reported that they fostered social interactions in groups and activities, they also admitted that they had difficulty motivating the majority of their clients to attend the groups and activities. Attendance at groups and activities is not mandatory. Greater numbers of clients attended the groups if transportation was provided. However, even with transportation provided, the participants reported an attendance rate at weekly groups of only about five to ten percent of their client population. The attendance rate at monthly recreational activities was higher, and was reported by the participants to be from ten to twenty percent, depending on the activity. For many of ACT's clients, their social relationships were limited to family members, and others remained isolated.

A review of the ACT's job descriptions provided by the research settings documented staff positions that reflected what ACT considered to be important. For example, because substance abuse has been recognized as an important detriment to recovery in this population, the teams include a substance abuse specialist. Likewise, because vocational work has been identified as a recovery goal, the teams all included vocational specialists. However, there was no job description for a social integration specialist and there was no one worker who takes the primary responsibility for providing regular opportunities for engagement around social and interpersonal issues. In this study, a nurse took it upon herself to arrange for social activities for the clients and their families. When additional work was added to her job load, she no longer had time to arrange social activities, and so they ended. The general lack of focus, with no embedded or formalized plan for social integration has been noted by other researchers (Angell, 2003; Calsyn et al., 1998; Krupa et al., 2005). If the importance of social interaction and enjoyable experiences for people with SMI was understood by ACT to be a motivating force that engaged their clients in the process of recovery, a social integration specialist would be added to the list of disciplines already included. The social integration specialist's professional expertise would enable them to design a group and activities program that would likely motivate more than the small percentage of ACT's clients that currently attend.

Meaning/Interpretation of Findings: Facilitating Social Integration through Independent/ Interdependent Functioning

Working closely with ACT workers, the clients learned skills required for independent function. The clients were taught how to food shop, take public transportation, use resources, do their banking and to achieve basic independent functioning skills. The method used by workers involved accompanying and guiding, but avoided any actions on their part that might replace the actions that the clients could possibly do for themselves. The aim was to promote independence.

Vocational goals such as volunteering, educational pursuits and competitive employment were encouraged; each team had a vocational specialist. An ACT team program director discussed vocational goals and explained that his agency's ACT teams had reached their vocational goals with thirty to forty percent of their clients engaged in vocational endeavors. According to the program director, that amount represented almost double the national average of 15-20 percent. The program director credited this success to very motivated, outgoing, and creative vocational specialists and teams who embodied the belief that their clients had the ability to be employed. While this agency's ACT teams had successfully exceeded the thirty percent goal of vocational involvement for their clients, the other ACT teams interviewed for this study struggled, with participants on those teams voicing their belief that employment was not a reasonable goal for the recommended thirty percent of their clients.

Vocational employment for people with SMI has been explored in the literature. Henry and Lucca (2004) conducted focus groups with service providers and

focus groups with people with SMI in order to determine the facilitators and barriers to employment. All of their study participants agreed on the need to enhance the clients' confidence in the idea that working could be beneficial for them. They emphasized the value that fostering respectful and trusting relationships between the client and his or her worker had on this process. Henry and Lucca's findings are consistent with the findings suggested by this study in that it is the trusting relationship between the client and worker that assists in moving the client forward toward recovery goals. In addition, several studies found that the low expectation of the workers regarding their clients' capability for employment was seen as a barrier to facilitating client employment in several studies (Gao & Dolce, 2010; Henry & Lucca, 2004). This is consistent with this study's finding that it is essential to have both a motivated employment specialist and "buy in" from a team that believes that employment is an important recovery goal and that the team's clients are capable of employment.

This study found that fear of losing entitlements such as social security disability benefits was also a major barrier to employment. A vocational specialist suggested that this was her greatest barrier in motivating clients for employment. Clients who were willing to work "off the books" were not willing to work a payroll job and have the amounts of their entitlements reduced, or cut altogether. This supports the findings of a number of studies that the fear of losing entitlements is a serious barrier to employment for people with SMI (Bond, Xie, & Drake, 2007; Henry & Lucca, 2004; Waynor & Pratt, 2010; Waynor & Pratt, 2011). Staff requires education to understand how their clients can work within the parameters of the entitlement

specifications without losing benefits, and they require training on how best to relay this information to their clients. Additionally, adjustment to the entitlement programs so that the person who suffers from SMI, a cyclical disease, need not fear the loss of entitlements would further eliminate this barrier to social integration.

In a quantitative study, Waynor and Pratt (2011) surveyed ACT workers to understand the barriers to vocational effectiveness. One recommendation was for the nurse to work with the newly employed ACT client in order to educate them about medication side effects and to maintain health and well-being. The findings of this study suggest that more is needed from the medical team. This study's participants provided examples of psychiatrically stable clients who failed at employment because they stopped taking their psychiatric medication in order to stay alert on the job. Subsequently they decompensated. This points to a need for the psychiatric medication prescriber and nurse to work closely with each newly employed client in order to adjust and monitor the medication as needed for both alertness and psychiatric stability.

Several participants suggested the need for employment opportunities that are attractive to the client. A secondary analysis of a longitudinal study of employed individuals with SMI noted the importance of job satisfaction in relationship to job tenure. Clients, who found their work to be both enjoyable and challenging, had increased rates of job retention (Kukla & Bond, 2012). Mueuser and Cook (2012) suggest that people with SMI be given the career development skills needed in order for them to achieve long term recovery goals of personally satisfying work in their area of interest.

Meaning/Interpretation of Findings: Housing

This study found that ACT workers believed inappropriate housing, dangerous neighborhoods, and homelessness were all barriers to facilitating social integration. These findings were particularly relevant to the ACT teams that served clients in urban and low income neighborhoods. ACT is not a housing program and does not have the resources to provide housing. A team leader suggested that the lack of housing resources for her clients was the biggest barrier she faced in facilitating social integration for her clients. These findings support those of Dorvil, Morin, Beaulieu, and Robert (2005) who found that access to suitable housing with supports was essential in preventing homelessness and an important factor in social integration for people with SMI. A more recent study by Kreindler and Cooden (2010) found that ACT improved housing stability and supported independent living for their clients.

Participants in this study suggested the need for appropriate, safe, and aesthetically pleasing housing for their clients. This is consistent with the findings of Borg and Davidson (2008) in which mentally ill participants described the importance of home as being a safe and pleasant refuge in which they could relax and replenish after their daily challenges. Calsyn et al. (1998) conducted randomized experiments to compare the effectiveness of ACT serving homeless mentally ill clients against other treatment modalities in order to determine if ACT facilitated a larger social network for their clients. They found that it did not; however, they did not take into account the disruption that homelessness inflicts. According to Maslow (1943), the hierarchy of human needs places safety (in this situation the necessity of finding shelter) as a clear

human priority above that of building social relationships. With adequate housing, people who were psychiatrically disabled and alcohol dependent made significant mental health improvements (Tsemberis, Kent, & Respress, 2012). Without enough housing resources, homelessness and inappropriate housing continues to remain a problem for ACT's clients.

Meaning/ Interpretation of Findings: Workers Suggest Innovative Solutions:

Creating Pathways to Enhance Social Integration

Unlike the usual provision of mental healthcare, ACT provides the bulk of its services in the client's home (Bond et al., 2001). According to a the program director at one agency in which the interviews took place, the agency's ACT teams began offering groups in order to fulfill the expectation of increased face to face hours mandated by the state. The initial intention of offering groups was not to provide for social interaction. However, once they began to provide groups, the teams realized that for the clients that attended these first groups, though unintended, they did receive the important benefit of social interaction with their peers.

Participants in this study explained that during that time in which a client receives mental health services from ACT, he or she is normally restricted from attending a day treatment program, as this is considered by insurance providers, as a duplication of services. The ACT client could not attend day treatment program that were staffed by the same disciplines as the ACT team, even if the social interaction that might be provided by a day program was seen as an opportunity for the client to develop the skills of social integration (cost of attendance would not be covered).

Sturm (2007) highlights some of the difficulties psychiatric community health nurses faced when their clients required interventions from multiple types of providers in more than one setting, but which were considered a duplication of services by the insurer and coverage was denied. Another team leader explained that her clients could only attend drop in centers that were not staffed by professionals, due to duplication of service issues. Because the state in which her ACT team was located had shut down the drop- in centers, her clients were seen sleeping on park benches during the day with nothing to do. Clearly, billing rules create barriers to the provision of complimentary services for clients.

When the workers were asked if they had any ideas for ways that they would like to try to facilitate social integration, eleven participants suggested ideas related to the provision of new groups and activities in addition to the educational programs already at the office. Participants found that clients did not see educational groups by themselves as a sufficiently attractive type of group to motivate client attendance. Suggestions for additional groups to be added were creative arts groups and yoga in addition to the usual educational groups. The creative arts have been used successfully to improve mental health (Grocke, Block, & Castle, 2008). Burick and McKelvey (2004) recommended the use of art as a healing process for people with SMI, especially for people who are withdrawn, or who have difficulty expressing themselves verbally. Barton (2011) combined yoga, dance and mindfulness techniques for a population with SMI, and received positive feedback from her group participants. According to the participants, the educational groups offered are attended by five to ten

percent of ACT's clients. The offering of creative arts groups as an adjunct to educational groups may motivate clients that are not interested in attending educational groups to come into the ACT office and will also provide more opportunities for social interaction.

ACT participants made several suggestions related to the idea of a drop-in center. These included using an area at an office space as a drop-in center within the agency for ACT clients to go to when they felt bored. Several participants believed that the clients would respond better to a drop-in situation than they would to any type of daily structured program. Participants also suggested a peer support group. If the ACT team does not have the staff to manage a drop-in center, especially when the majority of their work is in the field, this would be an opportunity to enlist the peer counselor and other ACT team clients to form a consumer run drop-in center (CRDIs) (Mowbray, Woodward, Holter, MacFarlane, & Bybee, 2009). These are peer run drop-in centers providing a safe environment in which the team's clients could come to socialize with their peers.

The ACT teams provided monthly community based outings for their clients. Over half of the participants interviewed suggested that the frequency of these community based outing groups be increased with several participants suggesting they be increased to at least weekly. These were better attended than the office-based groups and according to the participants they were able to engage ten to twenty percent of the clients. The types of activities suggested were the same kinds of activities that the general population participates in, such as bowling, going to the movies, or sharing a

meal at a restaurant. These are also the same type of everyday activities that Davidson, Stayner et al. (2001) described as simple, but very important to people with SMI who yearn for social inclusion. In addition, social activities have been shown to increase self-esteem in people with SMI. Frank and Davidson (2012) found that the individuals interviewed were able to maintain a high sense of self-esteem, in part, through participation in social and interpersonal activities.

Several new ideas for types of outings that would be new for these agencies were also suggested; a participant explained that most ACT clients had never taken a vacation, and camping was suggested as an affordable possibility that would provide a new and pleasurable experience for ACT clients. Additional community outing ideas were visiting museums or nearby cities, so that clients might be inspired by having new experiences. Davidson et al. (2006) reminded us that the value of fun and pleasurable experiences in the lives of people with SMI should not be undervalued. Not only do they provide the person with something to look forward to, but they also counteract the despair that may accompany their mental illness.

Several participants emphasized the need for an activities specialist who could coordinate the office based groups and community outings. A regular staff position of social integration specialist could be incorporated into the ACT model as a regular member of the team, similar to the vocational, or substance abuse specialist. The social integration specialist could be responsible for offering and motivating clients to attend an appealing program including office based activities and community outings aimed at facilitating social integration. The social integration specialist might be assisted by the

peer counselor in organizing the program and motivating clients. Both a peer counselor and a team leader suggested that the peer counselor would be well suited to facilitating community activities and motivating clients. Peers have been shown to be effective at engaging and supporting peers, thus decreasing the social isolation often experienced by people with SMI (Schon, 2010; Schutt & Rogers, 2009).

Participants in this study also shared ideas to promote the independent functioning and vocational goals of social integration. Several participants recommended a community garden that would be taken care of by ACT clients. The clients would also be involved in the sale of the produce to their urban community. Social therapeutic horticultural has been used with the mentally ill and other vulnerable populations and been shown to be effective in building self-esteem, well-being and providing a feeling of inclusion for vulnerable populations including people with SMI (Sempik, Aldredge, & Becker, 2005). It has also been shown to improve the quality of life domains of life satisfaction, well-being and self-concept, (Perrins-Margalis, Rugletic, Schepis, Stepanski & Walsh, 2000). The question of space for a garden was addressed by the participants when they suggested that the flat roof of their urban ACT office could be turned into a garden.

Strengths and Limitations of the Study

The main strength of this study is its ability to incorporate the views of a group of diverse frontline ACT workers representing a variety of disciplines that serve on seven ACT teams across two northeastern states. The clients served by these ACT teams lived in rural, suburban, and urban low-income neighborhoods, thus increasing

the likelihood of transferability to other ACT teams. The inclusion of two focus groups in addition to individual interviews and a document review provided triangulation; and, increased the credibility of this study. One limitation of this study is that no family specialists or psychiatrists were interviewed, therefore limiting valuable insight that may have been gleaned from those interviews. Also, although very successful vocational specialists were described by a program director, those vocational specialists were not available to be interviewed in this study. Those interviews might have provided valuable information for other vocational specialists who are struggling with the issue of client employment. This is an area of concern that requires further research. Another limitation of this study is that the populations served by the various teams may have differed in their baseline functional capacities, although all met the criteria of frequent psychiatric hospitalizations.

Implications for Nursing and Research

It is important to recognize that all people, including people with SMI, need satisfying social interaction. The participants believed that it was through a slow and individualized engagement process that trusting relationships developed. It is noteworthy that the participants believed that it was the trusting interpersonal relationship that developed between the worker and the client that was the most important factor for motivating the client towards recovery goals. In a study on self-esteem, people with SMI understood the concept of social integration to mean having significant social relationships (Frank & Davidson, 2012). In a qualitative study investigating the personal recovery process, the study participants believed that

recovery was primarily a social process with supportive and encouraging relationships as key components (Mancini, Hardiman, & Lawson, 2005).

The ACT teams utilized groups and community activities to facilitate the social process by providing opportunities for socialization with peers. Social skills were enhanced by the client's participation in groups, and the participation in evidence based programs such as WRAP (Cook et al., 2009) and IMR (Mueser et al., 2002). In addition to the educational groups already offered, the clients' social skills could be enhanced by offering a program of Social Skills Training, an evidenced based educational program designed specifically to enhance social skills in people with SMI (Bellack, 2004; Bellack, Mueser, Gingerich, & Agresta, 2004). Additional programs to consider include Pathways to Recovery (PTR), a peer-led program that helps people with SMI find meaning and purpose in their lives (Fukui, Davidson, Holter, & Rapp, 2010). Another program worthy of consideration for improving social functioning in ACT clients is social cognition and interaction training (SCIT) an intervention specifically focused at addressing the social cognitive difficulties and faulty emotional perceptions associated with schizophrenia (Roberts & Penn, 2009). In order to address internal stigma, Sibitz, Unger, Woppmann, Zidek, and Amering (2011) proposed the teaching of stigma resistance (the experience of resisting or being unaffected by stigmatizing attitudes) to people with SMI enabling them to be less susceptible to internalized stigma.

In addition to the educational groups offered by the ACT program, the findings of this study also suggest the provision of greater variety of groups and activities,

including the creative arts, to be offered to the clients. Participants reported that many clients did not see educational groups by themselves, sufficiently attractive to motivate attendance.

Social integration into the community was facilitated for the clients by providing opportunities for recreational social interaction with peers. These social opportunities were provided only once a month. The findings of this study suggest the need for more frequent social recreational activities for their clients. To increase client social interaction, without using staff work hours, ACT teams could utilize “engineered relationships” an intervention used by an ACT team studied by Angell (2003), in which clients thought by staff to be potentially compatible were given the resources needed to pair up and enjoy a social activity together in the community.

The findings of this study suggest the need for a social integration specialist to become an embedded member of the ACT team and to be responsible for the design of a social integration program, providing a targeted focus on this goal for the clients of ACT. The social integration specialist could work in unison with the peer counselor who would be well suited to assist in motivating clients to leave their homes to socialize, attend groups and join weekly social community activities (Schutt & Rogers, 2009). This study also found the expressed need by several study participants for an ACT drop-in space that clients could come to when they were bored or needed companionship.

Wong, Sands, & Solomon (2010) asserted that people with SMI have lifelong identities other than that of being a consumer of psychiatric services. A participant is

this study expressed the same idea when she said that people with SMI should socialize around the activity they were engaged in and not around mental illness. All of ACT's interventions designed to increase community involvement focused on bringing groups of peers into the community to socialize with each other. The participants in this study described ACT clients who were artists, poets, book lovers, and animal lovers. ACT workers might also benefit their clients by focusing on clients' strengths and individual interests and supporting them to meet and maintain social interaction with others in the community, mentally ill or not, who share the same interests. Examples of these types of community offered activities include: free or low cost community classes, art gallery openings, poetry readings, creative writing programs, religious organizations, cultural organizations and events, and dance groups.

Another avenue for reciprocal social interaction in the community is through volunteer programs. In this way the clients can offer something back to the community. This study provided an example of a client volunteering at an animal shelter. ACT clients can also volunteer time at organizations such as the National Alliance on Mental Illness (NAMI), an organization devoted to advocacy for people with SMI and their families. This study's participants identified employment as an important factor in social integration. For individuals with little work experience, volunteering may be one way of beginning the work process and developing the experience and confidence needed for the next step.

Helping people with SMI to attain employment goals is an important step in the recovery process and it appears to require that the worker can convey to the client a

shared and strong belief in the client's ability to achieve the identified employment goal. It will also require the availability of work that people with mental illness find engaging, as well as workplaces that are sensitive to and supportive of people with SMI. People with SMI require appropriate accommodations at employment sites, similar to those that are now required for any other type of disability. To assist clients in job tenure and other employment goals the psychiatric medication prescriber and nurse should work closely with each newly employed client in order to adjust and monitor their medication as needed for both alertness and psychiatric stability.

Future areas of research should include the ways in which successful and motivated workers form strong trusting relationships with their clients and the ways in which these relationships could be strengthened and used to promote recovery goals. Research should be done to determine if the inclusion of social integration goals on treatment plans regarding assisted social interaction with peers and others in the community would affect the clients' social integration outcomes. Another avenue of research could test interventions that bring clients of ACT into the community to interact with others not involved with ACT, around topics not limited to mental illness. Research should be conducted to determine if the addition of a social integration specialist, the use of peer assisted socialization, together with an embedded focus on socialization and recreation will motivate clients toward recovery goals, and aid in the facilitation of social integration for ACT's clients.

Nurses care for people with SMI for psychiatric and medical reasons, and do so in diverse settings which include the community, the emergency room, or even the

delivery room. In whatever capacity nurses assist people with SMI they can facilitate social integration for this population by treating them as valuable members of society, and with the same respect and dignity that all people served by nurses deserve.

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Appendix A

LETTERS OF SOLICITATION

Letter of Solicitation for Facilitating Social Integration for People with Severe Mental Illness

You are being asked to participate in the qualitative study "Facilitating Social Integration for People with Severe Mental Illness" because you are a staff person on a Program for Assertive Community Treatment (PACT) team who has had personal firsthand experience with the research topic.

Affiliation

My name is Sheila Linz and I am an advanced practice nurse and a doctoral student at Seton Hall University, College of Nursing. I am the Nurse Researcher who designed the study "Facilitating Social Integration for People with Severe Mental Illness" under the guidance of Dr. Bonnie Sturm, Associate Professor at The Seton Hall University College of Nursing.

Purpose of the study

The purpose of the study is to explore and describe the experience of the worker on a PACT team, surrounding their efforts to facilitate social integration for the client with severe mental illness. As a PACT team worker with professional experience working on the front lines, you have a valuable and unique perspective to share on the research topic.

Participation Time

60-90 minutes

Study Procedure

After signing an informed consent, you will be interviewed by the researcher for 60-90 minutes and asked open ended questions about your experience and your perspectives on facilitating social integration for clients with severe mental illness who receive PACT services. Please do not use any client's names in speaking about your experience. If you do use a client's name, the name will not be included in the typed transcript of your interview. Typical questions that you will be asked will be about how you personally define social integration, methods you may have tried, successes and failures, and possible barriers you may have encountered in your efforts to facilitate social integration for your clients. The interview will be audio taped. Your name and all names mentioned in the interview will be eliminated with original names not included in the typed transcript of the interview.

You will be given a stamped envelope addressed to the researcher in case you later think of anything further that you would like to add by writing your ideas and mailing them. You will also be given a phone number so that you could call the researcher if you think of any information that you would like to add (the phone call will be audio taped), or you could email your additional thoughts to the researcher.

Participation is Voluntary

Participation in the qualitative study "Facilitating Social Integration for People with Severe Mental Illness" is completely voluntary. Participation or non participation will have no effect on your employment experience whatsoever. It will not affect your appraisal ratings or the way that you are treated by supervisory staff.

If you do decide to participate, you may change your mind and end your participation in the research study or cut the interview short at any time. You do not have to give a reason for ending your participation.

Anonymity

Data will be collected without any identifying information. The data collected from each study participant will not be anonymous to the researcher; however the researcher will eliminate all names connected to the data so that it will not be able to be identified by anyone else. Except for the signature on the consent form, your name will not appear at any point in the research study. The consent form will be kept in a secure locked site in the researcher's home, separate from your interview and will not be able to be linked to your interview.

Confidentiality

No names, addresses or other identifying information will be attached to the information that you provide.

All recorded data will be stored only on a USB memory key or CD and kept in a secure, locked site in the researcher's home. The recorded data will be kept for a period of three years after the completion of the study and then deleted. A typed transcript of the data will be kept for a period of at least three years after the completion of the study. The only people to read the typed transcripts will be the researcher and her university advisor. The typed transcripts will be kept by the researcher in a separate locked and secure site in her home.

If you have any further questions, or would like to participate in the study, you may email me at [sheila.linz@student.shu.edu]

Letter of Solicitation for Facilitating Social Integration for People with Severe Mental Illness

You are being asked to participate in the qualitative study "Facilitating Social Integration for People with Severe Mental Illness" because you are a staff person on an Assertive Community Treatment (ACT) team who has had personal firsthand experience with the research topic.

Affiliation

My name is Sheila Linz and I am an advanced practice nurse and a doctoral student at Seton Hall University, College of Nursing. I am the Nurse Researcher who designed the study "Facilitating Social Integration for People with Severe Mental Illness" under the guidance of Dr. Bonnie Sturm, Associate Professor at The Seton Hall University College of Nursing.

Purpose of the study

The purpose of the study is to explore and describe the experience of the worker on an ACT team, surrounding their efforts to facilitate social integration for the client with severe mental illness. As an ACT team worker with professional experience working on the front lines, you have a valuable and unique perspective to share on the research topic.

Participation Time

60-90 minutes

Study Procedure

After signing an informed consent, you will be interviewed by the researcher for 60-90 minutes and asked open ended questions about your experience and your perspectives on facilitating social integration for clients with severe mental illness who receive ACT services. Please do not use any client's names in speaking about your experience. If you do use a client's name, the name will not be included in the typed transcript of your interview. Typical questions that you will be asked will be about how you personally define social integration, methods you may have tried, successes and failures, and possible barriers you may have encountered in your efforts to facilitate social integration for your clients. The interview will be audio taped. Your name and all names mentioned in the interview will be eliminated with original names not included in the typed transcript of the interview.

You will be given a stamped envelope addressed to the researcher in case you later think of anything further that you would like to add by writing your ideas and mailing them. You will also be given a phone number so that you could call the researcher if you think of any information that you would like to add (the phone call will be audio taped), or you could email your additional thoughts to the researcher.

Participation is Voluntary

Participation in the qualitative study "Facilitating Social Integration for People with Severe Mental Illness" is completely voluntary. Participation or non participation will have no effect on

your employment experience whatsoever. It will not affect your appraisal ratings or the way that you are treated by supervisory staff.

If you do decide to participate, you may change your mind and end your participation in the research study or cut the interview short at any time. You do not have to give a reason for ending your participation.

Anonymity

Data will be collected without any identifying information. The data collected from each study participant will not be anonymous to the researcher; however the researcher will eliminate all names connected to the data so that it will not be able to be identified by anyone else. Except for the signature on the consent form, your name will not appear at any point in the research study. The consent form will be kept in a secure locked site in the researcher's home, separate from your interview and will not be able to be linked to your interview.

Confidentiality

No names, addresses or other identifying information will be attached to the information that you provide.

All recorded data will be stored only on a USB memory key or CD and kept in a secure, locked site in the researcher's home. The recorded data will be kept for a period of three years after the completion of the study and then deleted. A typed transcript of the data will be kept for a period of at least three years after the completion of the study. The only people to read the typed transcripts will be the researcher and her university advisor. The typed transcripts will be kept by the researcher in a separate locked and secure site in her home.

If you have any further questions, or would like to participate in the study, you may email me at [sheila.linz@student.shu.edu]

Letter of Solicitation (focus group)

Facilitating Social Integration for People with Severe Mental Illness

You are being asked to participate in the qualitative study "Facilitating Social Integration for People with Severe Mental Illness" because you are a staff person on a Program for Assertive Community Treatment (PACT) team who has had personal firsthand experience with the research topic.

Affiliation

My name is Sheila Linz and I am an advanced practice nurse and a doctoral student at Seton Hall University, College of Nursing. I am the Nurse Researcher who designed the study "Facilitating Social Integration for People with Severe Mental Illness" under the guidance of Dr. Bonnie Sturm, Associate Professor at The Seton Hall University College of Nursing.

Purpose of the study

The purpose of the study is to explore and describe the experience of the worker on a PACT team, surrounding their efforts to facilitate social integration in the client with severe mental illness. As a PACT team worker with professional experience working on the front lines, you have a valuable and unique perspective to share on the research topic.

Participation Time

60 minutes

Study Procedure

After signing an informed consent, you and other participating members of your PACT team will be asked open-ended questions about your experiences and your perspectives on facilitating social integration for clients with severe mental illness who receive PACT services. Please do not identify any clients by name during the focus group session. However, if a client's name is mentioned it will not be included in the typed transcription of the focus group session. Typical questions that you will be asked will be about how you define social integration, methods you may have tried, and possible barriers you may have encountered in your efforts to facilitate social integration for your clients. The interview will be audio taped. Your name will not be connected in any way to the comments you make while participating in the focus group session. Your name and all names mentioned in the focus group session will be eliminated with the original names not included in the typed transcript of the focus group session.

Participation is Voluntary

Participation in the focus group session for the qualitative study "Facilitating Social Integration for People with Severe Mental Illness" is completely voluntary. Participation or non participation will have no effect on your employment experience whatsoever. It will not affect your appraisal ratings or the way that you are treated by supervisory staff.

If you do decide to participate, you may change your mind and end your participation in the focus group session at any time without any explanation.

Anonymity

Data will be collected without any identifying information. Except for the signature on the consent form, your name will not appear at any point in the research study. The data collected from each study participant during the focus group session will not be anonymous to the researcher or to the other members of the focus group session; however, the researcher will eliminate all names connected to the data so that it will not be able to be identified by anyone other than the researcher or participating members of the focus group. The consent form will be kept in a secure locked site in the researcher's home, separate from the focus group session data and will not be able to be linked to that data.

Confidentiality

No names, addresses or other identifying information will be attached to the information that you provide. All recorded data will be stored only on a USB memory key or CD and kept in a secure, locked site in the researcher's home. The recorded data will be kept for a period of three years after the completion of the study and then deleted. A typed transcript of the data will be kept for a period of at least three years after the completion of the study. The only people to read the typed transcripts will be the researcher and her university advisor. The typed transcripts will be kept by the researcher in a separate locked and secure site in her home.

If you have any further questions, or would like to participate in the study, you may email me at [sheila.linz@student.shu.edu]

Appendix B

INFORMED CONSENT FORMS

Consent for Participation in Research (individual interview)

Title of Study: Facilitating Social Integration for People with Severe Mental Illness

Investigator: Sheila Linz, MSN, PMHNP-BC

1. Researcher's Affiliation: The researcher is a doctoral student in the College of Nursing at Seton Hall University.

2. Purpose of Research: The purpose of this qualitative research is to explore and describe the experience of the worker on a Program for Assertive Community Treatment team (PACT), surrounding their efforts to facilitate social integration in the client with severe mental illness.

Duration: The expected duration of the study participant's' interview process is of approximately 60-90 minutes.

3. Procedures: After signing an informed consent, the study participant will be interviewed by the researcher for 60-90 minutes and asked open ended questions about their experiences and perspectives on facilitating social integration for clients with severe mental illness who receive PACT services. The interview will be audio taped. Client's names should not be used in the interview, however, if a client's name is used it will not be included in the typed transcript of the interview. A stamped envelope addressed to the researcher at Seton Hall University will be given to the study participant in the case that the study participant wishes to later add ideas and thoughts to their interview related to the research questions. Alternatively the researcher may be contacted by phone (the phone call will be audio taped), or emailed with additional information in the case that the study participant wishes to add information to their interview.

4. Typical Interview Questions: Typical questions that will be asked will be about how social integration is defined by individual PACT workers, methods that may have been tried, and possible barriers encountered in efforts to facilitate social integration for PACT clients.

5. Voluntary Nature of Participation: Participation in the study "Facilitating Social Integration for People with Severe Mental Illness" is completely voluntary. The study participant may choose to withdraw without giving a reason, from the interview and the study at any time and not be penalized in any way whatsoever. Participation or non participation will have no effect on employment experience. It will not affect appraisal ratings or treatment by supervisory staff.

6. Anonymity: Data will be collected without any identifying information. The researcher will be aware of the participant's identity, but except for the signature on the consent form, names will not appear at any point in the research study. The consent form will be kept in a secure locked site in the researcher's home, separate from the interview and will not be able to be linked to the study participant personally.

7. Confidentiality: No names, addresses or other identifying information will be attached to the information that the study participant provides. All recorded data will be stored only on a USB memory key or CD and kept in a secure, locked site in the researcher's home. The recorded data will be kept for a period of three years after the completion of the study and then deleted.

8. Confidentiality of Records: A typed transcript of the data will be kept for a period of at least three years after the completion of the study. The only people to read the typed transcripts will be the researcher and her university advisor. The typed transcripts will be kept by the researcher in a separate locked and secure site in her home.

9. Risks: There is no anticipated risk for participating in the study. The questions that will be asked are about perceptions in relation to work experience with people who receive PACT services. If feelings of distress are experienced at any time related to the research study, the researcher should be called and she will refer the study participant to either the agency's employee counseling center, or if preferred, to an outside counseling service at the study participants own cost.

10. Benefits: Direct benefit may not be experienced by participating in the study, however, potential benefits to participating in the research project include providing insight to the mental health field on the ways in which social integration can be facilitated for PACT clients. Participation in the study by focusing on and discussing methods used by the study participants in their attempts to facilitate social integration for PACT clients may help improve the quality of service provided by the study participants to their clients. In addition, this is an opportunity for PACT workers to voice their individual perspectives and personal ideas on this important issue. At the completion of the project the researcher will offer to present the general findings of the study at the workplace, these general findings may be used to improve the quality of the services provided to all of those who work on or receive services from PACT.

11. Financial Remuneration: There will be no financial remuneration for participating in the study.

12. Compensation: There is no other form of compensation for participating in the study.

13. Alternative Procedures: Participation in the study voluntary.

14. Contact information: Participants with questions may contact the primary researcher, Sheila Linz PMHNP-BC at the PhD Nursing Program at the College of Nursing, Seton Hall University, 973-761-9266, or by cell phone at 609-462-7311, or by email at [sheila.linz@student.shu.edu]. The researcher's faculty advisor is Dr. Bonnie Sturm at Seton Hall University, College of Nursing and can be reached at 973-761-9762, or by email at [bonnie.sturm@shu.edu].

IRB: Address Phone # The Institutional Review Board at Seton Hall University can also be contacted for answers to any pertinent questions about the research and the study participant's rights and can be contacted by calling Dr. Mary Ruzicka at 973-313-6314, or by email at [irb@shu.edu]

15. Audio-Tapes: The interview will be tape recorded and listened to only by the primary researcher, her faculty advisor, and the transcriber. The audio tapes will be transcribed either by the researcher or a professional transcriber. The audio tape will not be labeled by name, but will be identified by a code number. The tape recorded interviews will be stored in a locked cabinet in the researcher's home for a period of three years after the completion of the study and then deleted.

16. Copy of Consent: The study participant will be given a copy of this signed and dated Consent Form.

By signing this consent form the study participant agrees to participate in an interview for the qualitative study "Facilitating Social Integration for People with Severe Mental Illness." It is understand that the interview will be audio taped. It is also understood that no financial remuneration will be received for participating in the study.

Study Participant _____ Date _____

Investigator _____ Date _____

Consent for Participation in Research (individual interview)

Title of Study: Facilitating Social Integration for People with Severe Mental Illness

Investigator: Sheila Linz, MSN, PMHNP-BC

1. Researcher's Affiliation: The researcher is a doctoral student in the College of Nursing at Seton Hall University.

2. Purpose of Research: The purpose of this qualitative research is to explore and describe the experience of the worker on an Assertive Community Treatment team (ACT), surrounding their efforts to facilitate social integration in the client with severe mental illness.

Duration: The expected duration of the study participant's interview process is of approximately 60-90 minutes.

3. Procedures: After signing an informed consent, the study participant will be interviewed by the researcher for 60-90 minutes and asked open ended questions about their experiences and perspectives on facilitating social integration for clients with severe mental illness who receive ACT services. The interview will be audio taped. Client's names should not be used in the interview, however, if a client's name is used it will not be included in the typed transcript of the interview. A stamped envelope addressed to the researcher at Seton Hall University will be given to the study participant in the case that the study participant wishes to later add ideas and thoughts to their interview related to the research questions. Alternatively the researcher may be contacted by phone (the phone call will be audio taped), or emailed with additional information in the case that the study participant wishes to add information to their interview.

4. Typical Interview Questions: Typical questions that will be asked will be about how social integration is defined by individual ACT workers, methods that may have been tried, and possible barriers encountered in efforts to facilitate social integration for ACT clients.

5. Voluntary Nature of Participation: Participation in the study "Facilitating Social Integration for People with Severe Mental Illness" is completely voluntary. The study participant may choose to withdraw without giving a reason, from the interview and the study at any time and not be penalized in any way whatsoever. Participation or non participation will have no effect on employment experience. It will not affect appraisal ratings or treatment by supervisory staff.

6. Anonymity: Data will be collected without any identifying information. The researcher will be aware of the participant's identity, but except for the signature on the consent form, names will not appear at any point in the research study. The consent form will be kept in a secure locked site in the researcher's home, separate from the interview and will not be able to be linked to the study participant personally.

7. Confidentiality: No names, addresses or other identifying information will be attached to the information that the study participant provides. All recorded data will be stored only on a USB memory key or CD and kept in a secure, locked site in the researcher's home. The recorded data will be kept for a period of three years after the completion of the study and then deleted.

8. Confidentiality of Records: A typed transcript of the data will be kept for a period of at least three years after the completion of the study. The only people to read the typed transcripts will be the researcher and her university advisor. The typed transcripts will be kept by the researcher in a separate locked and secure site in her home.

9. Risks: There is no anticipated risk for participating in the study. The questions that will be asked are about perceptions in relation to work experience with people who receive ACT services. If feelings of distress are experienced at any time related to the research study, the researcher should be called and she will refer the study participant to either the agency's employee counseling center, or if preferred, to an outside counseling service at the study participants own cost.

10. Benefits: Direct benefit may not be experienced by participating in the study, however; potential benefits to participating in the research project include providing insight to the mental health field on the ways in which social integration can be facilitated for ACT clients. Participation in the study by focusing on and discussing methods used by the study participants in their attempts to facilitate social integration for ACT clients may help improve the quality of service provided by the study participants to their clients. In addition, this is an opportunity for ACT workers to voice their individual perspectives and personal ideas on this important issue. At the completion of the project the researcher will offer to present the general findings of the study at the workplace, these general findings may be used to improve the quality of the services provided to all of those who work on or receive services from ACT.

11. Financial Remuneration: There will be no financial remuneration for participating in the study.

12. Compensation: There is no other form of compensation for participating in the study.

13. Alternative Procedures: Participation in the study voluntary.

14. Contact information: Participants with questions may contact the primary researcher, Sheila Linz PMHNP-BC at the PhD Nursing Program at the College of Nursing, Seton Hall University, 973-761-9266, or by cell phone at 609-462-7311, or by email at [sheila.linz@student.shu.edu]. The researcher's faculty advisor is Dr. Bonnie Sturm at Seton Hall University, College of Nursing and can be reached at 973-761-9762, or by email at [bonnie.sturm@shu.edu].

IRB: Address Phone # The Institutional Review Board at Seton Hall University can also be contacted for answers to any pertinent questions about the research and the study participant's rights and can be contacted by calling Dr. Mary Ruzicka at 973-313-6314, or by email at [irb@shu.edu]

15. Audio-Tapes: The interview will be tape recorded and listened to only by the primary researcher, her faculty advisor, and the transcriber. The audio tapes will be transcribed either by the researcher or a professional transcriber. The audio tape will not be labeled by name, but will be identified by a code number. The tape recorded interviews will be stored in a locked cabinet in the researcher's home for a period of three years after the completion of the study and then deleted.

16. Copy of Consent: The study participant will be given a copy of this signed and dated Consent Form.

By signing this consent form the study participant agrees to participate in an interview for the qualitative study "Facilitating Social Integration for People with Severe Mental Illness." It is understood that the interview will be audio taped. It is also understood that no financial remuneration will be received for participating in the study.

Study Participant _____ Date _____

Investigator _____ Date _____

Page 2, Participants Initials _____

Consent for Participation in Research (focus group)

Title of Study: Facilitating Social Integration for People with Severe Mental Illness
Investigator: Sheila Linz, MSN, PMHNP-BC

1. Researcher's Affiliation: The researcher is a doctoral student in the College of Nursing at Seton Hall University.

2. Purpose of Research: The purpose of this qualitative research is to explore and describe the experience of the worker on a Program for Assertive Community Treatment team (PACT), surrounding their efforts to facilitate social integration in the client with severe mental illness.

Duration: The expected duration of the study participant's interview process is of approximately 60 minutes.

3. Procedures: After signing an informed consent, willing participating members of a PACT team will be asked open-ended questions about their experiences and perspectives on facilitating social integration for clients with severe mental illness who receive PACT services. The focus group session will be audio taped. Client's names should not be used in the focus group session, however, if a client's name is used it will not be included in the typed transcript of the focus group session.

4. Typical Interview Questions: Typical questions that will be asked will be about how social integration is defined by individual PACT workers, methods that may have been tried, and possible barriers encountered in efforts to facilitate social integration for PACT clients.

5. Voluntary Nature of Participation: Participation in the study "Facilitating Social Integration for People with Severe Mental Illness" is completely voluntary. The study participant may choose to withdraw without giving a reason, from the focus group session and the study at any time and not be penalized in any way whatsoever. Participation or non participation will have no effect on employment experience. It will not affect appraisal ratings or treatment by supervisory staff.

6. Anonymity: Data will be collected without any identifying information. Except for the signature on the consent form, names will not appear at any point in the research study. The consent form will be kept in a secure locked site in the researcher's home, separate from the focus group data and will not be able to be linked to the study participant personally. The researcher and the other focus group members will be aware of what has been said during the focus group session.

7. Confidentiality: No names, addresses or other identifying information will be attached to the information that the study participant provides. All recorded data will be stored only on a USB memory key or CD and kept in a secure, locked site in the researcher's home. The recorded data will be kept for a period of three years after the completion of the study and then deleted.

8. Confidentiality of Records: A typed transcript of the data will be kept for a period of at least three years after the completion of the study. The only people to read the typed transcripts will be the researcher and her university advisor. The typed transcripts will be kept by the researcher in a separate locked and secure site in her home.

Page 1, Participant Initials

9. Risks: There is no anticipated risk for participating in the study. The questions that will be asked are about perceptions in relation to work experience with people who receive PACT services. If feelings of distress are experienced at any time related to the research study, the researcher should be called and she will refer the study participant to either the agency's employee counseling center, or if preferred, to an outside counseling service at the study participants own cost.

10. Benefits: Direct benefit may not be experienced by participating in the study, however, potential benefits to participating in the research project include providing insight to the mental health field on the ways in which social integration can be facilitated for PACT clients. Participation in the study by focusing on and discussing methods used by the study participants in their attempts to facilitate social integration for PACT clients may help improve the quality of service provided by the study participants to their clients. In addition, this is an opportunity for PACT workers to voice their individual perspectives and personal ideas on this important issue. At the completion of the project the researcher will offer to present the general findings of the study at the workplace, these general findings may be used to improve the quality of the services provided to all of those who work on or receive services from PACT.

11. Financial Remuneration: There will be no financial remuneration for participating in the study.

12. Compensation: There is no other form of compensation for participating in the study.

13. Alternative Procedures: Participation in the study voluntary.

14. Contact information: Participants with questions may contact the primary researcher, Sheila Linz PMHNP-BC at the PhD Nursing Program at the College of Nursing, Seton Hall University, 973-761-9266, or by cell phone at 609-462-7311, or by email at [sheila.linz@student.shu.edu]. The researcher's faculty advisor is Dr. Bonnie Sturm at Seton Hall University, College of Nursing and can be reached at 973-761-9762, or by email at [bonnie.sturm@shu.edu].

IRB: Address Phone # The Institutional Review Board at Seton Hall University can also be contacted for answers to any pertinent questions about the research and the study participant's rights and can be contacted by calling Dr. Mary Ruzicka at 973-313-6314, or by email at [irb@shu.edu]

15. Audio-Tapes: The focus group session will be tape recorded and listened to only by the primary researcher, her faculty advisor, and the transcriber. The audio tapes will be transcribed either by the researcher or a professional transcriber. The audio tape will not be labeled by name, but will be identified by a code number. The tape recorded interviews will be stored in a locked cabinet in the researcher's home for a period of three years after the completion of the study and then deleted.

16. Copy of Consent: The study participant will be given a copy of this signed and dated Consent Form.

By signing this consent form the study participant agrees to participate in a focus group session for the qualitative study "Facilitating Social Integration for People with Severe Mental Illness." It is understand that the focus group session will be audio taped. It is also understood that no financial remuneration will be received for participating in the study.

Study Participant _____ Date _____

Investigator _____ Date _____

Page 2, Participants Initials

Appendix C
INTERVIEW GUIDE

Interview Guide for Facilitating Social Integration

1. What does the term "social integration for the mentally ill" mean to you?
2. How do you go about engaging with your client?
3. How would you describe the relationships you have with your clients?
4. What are your perceptions about the social relationships your clients have?
5. How do you go about developing your client's social skills?
6. What methods, if any, have you have used in order to try to facilitate your client's social integration into the community?
7. What are some examples of successes or failures?
8. What are some of the obstacles or barriers you face in attempting social integration for your client?
9. Do you have any ideas for ways that you would like to try to facilitate social integration for your clients if you could?
10. Is there anything more that you would like to add about this topic?