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# Community Integration and Normalization

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Philadelphia College of Osteopathic Medicine

Department of Psychology

COMMUNITY INTEGRATION AND NORMALIZATION

By Janice Eileen Cunningham

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of the Requirements for the Degree of  
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**Dissertation Approval**

**This is to certify that the thesis was presented to us by Janice Eileen Cunningham on August 1, 2003, in partial fulfillment of the requirements for the degree of Doctor of Psychology, has been examined and is acceptable in both scholarship and literary quality.**

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## Abstract

Utilizing archived data for 650 individuals, psychosocial variables were examined to elucidate the effect of deinstitutionalization on success of community integration.

Deinstitutionalization has been blamed for a host of societal ills including the burgeoning homeless population and for overcrowding in prisons. Many claim that deinstitutionalization has failed and that the chronically severely mentally ill have not become part of their communities. Utilizing extant data on consumers released from Pennsylvania state hospitals as part of a unique initiative, the psychosocial variables of age, race, gender, length of institutionalization, placement following hospitalization and diagnosis were correlated with homelessness, incarceration, or whereabouts known to measure rate of community integration. Of all living consumers released under this initiative, 97% are living in the community.

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# Chapter 1

## Introduction

The topic of community integration and normalization is complex. Not only is it multifarious but it is also extremely controversial. It refers specifically to releasing adults, many who may have spent the greater number of their adult years in a state mental institute, back into the community. It means that people who have accepted the protective environment of the hospital as home need to learn to live outside the confines of the walls of an institution and become skilled at navigating the complexity of living in a fast-paced, ever-changing, and often unwelcoming world. To truly achieve integration means that a vulnerable population has access to the same resources as everyone else. It means they can live fully and normally without any confines, coming and going at will and making decisions about their lives and futures. It means living openly in neighborhoods and being exposed to the same challenges, choices and chances at success as every other adult in our society.

It is precisely this free will that many objectors believe expose the severely mentally ill to undue and unmanageable stresses. They further believe that these life-threatening stresses are directly linked to the advent of deinstitutionalization. Deinstitutionalization is certainly marked by successes and failures. The decision to not only allow this vulnerable population of mentally ill persons to be released into the community but to actively promote it, is venerated by a long and convoluted history that is briefly outlined in the beginning of this

chapter. As controversial a topic today as it was centuries ago, the deinstitutionalization movement has as many challengers as it does proponents.

The opponents suggest that deinstitutionalization has resulted in a society in crisis as the country copes with a seemingly unprecedented homeless population and prisons distended with mentally ill patients, rather than with bona fide criminals. They disparage the fact that susceptible individuals appear to not receive care and treatment and surmise that the severely mentally ill lead lives that are vacant and meaningless, suggesting that these individuals, and society in general, are perhaps better served by the previous domain of infinite hospitalization.

Those who promote the inclusion of the severely mentally ill into communities cite the success and refute the dogma outlined by their opponents. They reference the subjective reports of increased independence and refute the belief that the former patients have disappeared into the streets or behind bars. They present evidence that the severely mentally ill are not only surviving, but also thriving, as they remain in treatment and even recover from their previously debilitating illnesses.

Each side has valid concerns and represents an interest that is equally troubled by societal ills. Each aspect of the debate has been evaluated with numerous attempts to understand the issue and to intervene in the most effectual manner to promote positive change, both for individuals, and for society as a whole. In order to accomplish this, however, there needs to be better consensus about the problem in general. To support this population of former

institutionalized individuals it is important to know just where they are. Not only is their location notable, but also it is important to understand if they truly are part of the homeless and jailed populations. If so, then what intervention will prevent this outcome in the future. If it can be proved that the previously institutionalized patients are not part of these marginalized populations of homeless and incarcerated individuals, then social policy and outreach may need to be tailored to better understand who the homeless really are. Then society can move forward with continual support of the deinstitutionalized individuals to further integrate this population in a meaningful and productive way into their communities.

The literature review that follows begins with a brief history and then presents both sides of the complicated issue with supportive critiques and research. The homeless question is examined, as well as the factors that exacerbate the condition including mental illness, addiction and contributing psychosocial variables. The problem of the mentally ill and incarceration is also explored in the same vein. This first chapter gives credence to both sides of the issue while also acknowledging some of the challenges deinstitutionalization continues to confront even as it attempts to resolve and close what may well be one of its own last chapters. The literature often presents strikingly opposing viewpoints that have created the questions this dissertation has been designed to illuminate and attempt to answer. These questions and resultant hypotheses are presented at the conclusion of the chapter. The remaining chapters of the study review the results and conclusions of the dissertation coupled with possible future

directions designed to gain additional knowledge regarding an ongoing and complicated issue.

### *Historical Background*

For many centuries those who suffer from severe mental illness have been shuffled in and out of view and back and forth between their communities and specialized facilities. Institutions or asylums, as they were initially known, first began to house citizens considered mentally ill or insane in the Middle Ages. Begun with the admirable intention of protecting the community and the individual, the goal was simply to remove the insane from visibility and keep them housed, fed and clothed. What was most important was that they were no longer seen by the greater populace. The intent eventually became lost, however, as overcrowding and ill management by unskilled and untrained workers led to allegations of abuse and neglect and the needs of this population became highly visible once again.

In the 19<sup>th</sup> century, with the acceptance that mental illness was actually treatable and even curable, state hospitals were erected to remove patients from poor houses, overcrowded asylums and other deplorable conditions to congregate sites where they would receive treatment and care funded by public resources. In the early part of the 20<sup>th</sup> century, large institutions continued to fulfill the societal need of housing the severely chronically mentally ill. Medications and treatment were only marginally effective, however, and these hospitals began to succumb to the same ills as their early predecessors. Following World War II the movement

for mental health hospital reform was begun in earnest. The need for reform was born out of concern after several thousand conscientious objectors served their military obligation by working in public psychiatric hospitals. Many of these objectors were shocked by conditions they observed and proceeded to make public accusations citing numerous incidents of abuse and mistreatment of patients. Once again the needs of a highly vulnerable section of society refused to remain hidden.

The advent of what became known as deinstitutionalization started with the reform movement begun by the conscientious objectors and other concerned mental health professionals. Deinstitutionalization simply means to remove the institute, or in the case of those mentally ill who are housed in an institution to remove them from it, and have them live in the community instead. In response to this reform movement, the National Institute of Mental Health was created stressing the pillars of research, training and services (Shore, 1992). It was followed by the Mental Health Study Act of 1955 and the Joint Commission on Mental Illness and Health with its recommendation in 1961 for community alternatives to state hospitals. The commission recommended that the needs of the mentally ill not be hidden, and that they live visibly again.

There was a conviction that these individuals would be better served closer to home with smaller community treatment alternatives versus treatment in a large institution. It was thought that patients could receive the same comprehensive services that they had previously received in state hospitals, while living freely among others. This became partly attainable with the development of

improved psychotropic medication and also when Aid to the Disabled, or Supplemental Security Income as it is now known, became available for mental health patients, as well as for those with physical disabilities. The effect was to shift some of the financial burden from the states to the federal government. In addition, federal grants became available to construct and staff new community mental health centers. The civil rights of mental health patients were also scrutinized and comprehensive changes in commitment laws were enacted. The result was that it became more difficult to commit psychiatric patients, and indefinite, unwilling commitments became obsolete.

The Community Mental Health Centers Construction Act called for a division of communities into catchment areas, which had the task of evaluating the needs of the mentally ill in their community and developing appropriate services. The law required that each catchment area provide inpatient services, partial hospital services, emergency services, outpatient services and community education and consultation (Shore, 1992). The underlying philosophy came to be known as the three C s: comprehensive, coordination and continuity of care, followed by the 4 A s of service delivery: accessibility, availability, acceptability and awareness (Shore, 1992). Patients began to be discharged to the community. The process of deinstitutionalization had begun.

The National Institute of Mental Health Task Force defines mentally ill persons as those having any severe and persistent disability ensuing from mental illness (Rothberg, Schinner & Goldman, 1996). To have the term severely mentally ill applied requires meeting both the above test and having some

functional limitation in activities of daily living, concentration, social interaction or adaptation to environmental changes. Lastly, the term persistent mental illness refers to duration in excess of 12 months. The Center for Mental Health Services applied these terms (severely persistently mentally ill) to an estimated 4.8 million to 10 million adults in the United States (Kessler, et al, 1996). This is the population that deinstitutionalization was targeted to assist.

### *Statement of the Problem*

It has been more than three decades since the first stirrings of deinstitutionalization began. What does it look like today? What happens to patients who are released into the community? Do we know where they are? Where do they live? Are they visible in their communities? Are they receiving treatment? What treatment are they receiving? Are there individual characteristics that assure successful community integration? Do some people have a better chance at success than others? There are many theories regarding these questions but the answers have been less clear. The problem is that many researchers claim that the mentally ill released from state hospitals are jailed, homeless or deceased but they base this assumption on data collected after the fact. They look at the jailed mentally ill or the homeless mentally ill and blame deinstitutionalization for the fate of these individuals. Researchers rarely look at what percentage of the chronically persistently mentally ill are actually being successfully integrated into the community. They do not examine the factors that make one individual more vulnerable to incarceration or homelessness than another, nor do they identify the

factors that may serve as protective and may help increase the ratio of successful community integration.

### *Scope of the Problem*

*Homelessness.* The topic of deinstitutionalization remains controversial and the literature has offered mixed answers to these questions. Senator Edward Kennedy, democratic senator from Massachusetts, in 1990 wrote that the mentally ill who have been deinstitutionalized often face isolation, despair and abandonment upon discharge from a state hospital. An article in the Washington Post in 1999 (Torrey & Zdandowicz, 1999) stated that, “hundreds of thousands of vulnerable Americans are eking out a pitiful existence on city streets, underground in subway tunnels or in jails and prisons due to the misguided efforts of civil rights advocates to keep the severely ill out of hospitals and out of treatment.” The authors further state that the needs of the mentally ill are not being met due to the loss of 93% of state hospital beds since 1955. An article in the Wall Street Journal in 1996 (Satel, 1996) stated that, “the passion for civil liberties at any cost is the legacy of the deinstitutionalization movement.” The article cited examples of patients who allegedly drain community resources and risk community safety. Yet another article by the Wall Street Journal (Torrey & Zdandowicz, 1998), stated that “increasing numbers of severely mentally ill individuals among the homeless population, incarcerated in jail and prisons for offenses committed while psychotic” are part of a larger pattern of violence that is a product of “deinstitutionalization gone awry.” Still others believe that



integration and normalization are myths. They believe that the mentally ill should stay hidden and that they were better off in large hospitals where they at least fit in with others and received treatment and care. They feel that community living means less care, inadequate care and insufficient support.

The previous statements were acknowledgments purported by concerned citizens but many researchers have also supported these beliefs. For example, Bachrach (1986) stated that the homeless mentally ill are a testimony to the failure of deinstitutionalization and the lack of a competent service model. Drake, Wallach, & Hoffman, (1989) concurred and further differentiated by claiming that young males had more difficulty being integrated into the community and were more likely to become homeless. Belcher expanded on these previous studies and in 1991 reported that 35% of those he studied became homeless after release from state mental hospitals.

Are the deinstitutionalized severely mentally ill disproportionately part of the homeless population? Not all researchers concur with the above authors. Rossi (1990) differentiates between the “old” and “new” homeless. From 1930-1960, the old homeless were mainly white, unmarried males approximately 50 years of age. Many were only intermittently employed with approximately one-fourth receiving Social Security benefits. Technically, they were homeless but rarely without shelter. At that time, there were flophouses, missions and cheap single- room occupancy hotels where the homeless could stay for extended periods of time if they chose. A study conducted in Chicago in the late 1950s (Kiesler, 1991a) found that 25% of the homeless were alcoholics, 20% had a

physical disability, 10% were maladjusted, 25% were just trying to live cheaply and 20% had a chronic mental health problems. The “new” homeless population began to appear in the 1980s and unlike their predecessors are often without shelter, young; females as much as males, children, and excessively from minority groups (Blasi, 1990). They seem to have reached their status as a result of economic and housing shortages (Blasi, 1990).

Kiesler (1991b) further disputed the belief that most homeless are mentally ill by stating that poverty is to blame. This was supported by Breakly and Fisher (1990) who reported homelessness as being the result of the lack of low- income housing and inadequate income support. Goodman, Saxe and Harvey (1991) hypothesized that it is homelessness itself that is a risk factor for persons to develop mental illnesses. “Homelessness makes people ill” according to Rafferty and Shin (1991). Homelessness became synonymous with shelterless during the 1980s when at least one-half of the single room occupancy hotels disappeared (Mapes, 1985). These authors and others argue against the seemingly popular notion that homelessness is a result of deinstitutionalization.

*Addiction and Gender.* While there is great disparity among researchers regarding the cause of homelessness as it relates to the deinstitutionalized mentally ill there does appear to be some consensus regarding the homeless population as it is associated with substance abuse. Investigators state that there appears to be some evidence that substance abuse may be a factor that makes the deinstitutionalized severely mentally ill more vulnerable to homelessness. Many

researchers argue that these released persons need specialized community services to prevent them from joining the statistical ranks of the homeless or incarcerated.

Susser, Lin and Conover (1991) report drug use other than alcohol to be correlated with homelessness among a mental health population. This belief is in opposition to Breakly and Fisher (1990), who note that homelessness and alcoholism are highly concurrent. The issue is complex because substance use may increase as a result of homelessness (Winkleby, Rockhill, Jatulis & Fortmann, 1992). Regardless, most researchers concur that substance use decreases the chance for successful community integration.

In another study of the homeless mentally ill, Casyn and Morse (1990) reported that men were homeless longer, had more criminal convictions, had greater alcohol problems but received the same mental health treatment as women. The issue of gender differences that affect the deinstitutionalized severely mentally ill and keep them from achieving successful community integration has been mixed. Benda (1987) put forth the hypothesis that men were more likely to “drift down” because of deviant activities but that women appeared to “drift down” as a result of decompensating mental health. “Drift down” was coined by Benda to mean personal deterioration as a result of crime, substance abuse and mental illness. In actuality he found that men did appear to have greater alcohol use and treatment, as well as imprisonments, but conversely women did not appear to have more psychiatric hospitalizations. Goering, Wasylenki, Onge, Paduchak, & Lancee, (1992) concurred and stated that there were no differences in gender for homelessness rates as a result of deteriorating mental health. This

was reported by Ritchey, La Gory and Mullis (1991) who found a greater number of deinstitutionalized mentally ill women among the homeless population they examined. Lamb and Lamb (1990) noted that women who had a prior history of institutionalization appeared to have more severe episodes of homelessness. Several other researchers also published similar results stating that men had more criminal involvement and women had more mental health treatment and lengthier hospitalizations than the homeless men (Burt & Cohen, 1989; D'Ercole & Struening, 1990). Mowbray et al. (1992) stated that the mentally ill homeless population was homeless longer, interfaced with the criminal system more, was more isolative and more often women, when compared with a nonmentally ill homeless population.

In direct opposition to some of the reported studies, there may actually be gender issues that serve as protective or mitigating factors that affect successful community integration. Research indicates that women usually have a less severe course of schizophrenia than their male counterparts (Mueser, Ballack, Morrison & Wade, 1990). They typically develop symptoms later in life (Angermeyer & Kuhn, 1988), have shorter periods of institutionalized treatment (Goldstein, 1988) and better long-term prognoses (Nymon & Jonsson, 1983). Although there appear to be biological defenses, it is also theorized that social factors may be partly responsible for the predicted better outcome for women. Among these is the belief that society accepts more deviant behavior in women, which may result in decreased stress; additionally, women may be subjected to less demand to conform to societal norms (Goldstein & Kreisman, 1988). In addition, women

may have had greater social skills prior to the onset of their illness (Leventhal, Schuck & Rothstein, 1984). In a study of community integration based on these findings, it would be predicted that women would have greater success than men but because women are typically hospitalized less and for shorter durations it could be assumed that women being discharged from a state hospital facility would be the more critically ill, which may equalize the prognosis for both genders.

*Imprisonment.* Thus far, the research on deinstitutionalization as it relates to this study, has examined the varied and often contradictory results researchers have reported regarding the success of long-term community inclusion for persons who have been previously institutionalized. Many researchers, and the community at large, dispute that there is inclusion by blaming the sorrow of homelessness on deinstitutionalization, although even among the proponents there is disagreement regarding the mitigating factors. Another social problem often blamed on deinstitutionalization is the overcrowding in the prisons.

French (1987) wrote that deinstitutionalization is not successful for the socially marginal person and therefore jails are overcrowded. Teplin (1983, 1990) reported that the predominance of severe mental illness among inmates was substantially higher than that of the population at large, which has led many researchers to conclude that mentally ill individuals are being incarcerated instead of being hospitalized. Phenomenally, this has been credited to failures in the mental health system rather than the criminal justice system (Abram and Teplin,

1991). The issue of the mentally ill being in jail versus being in the mental health system is not a new one. Penrose (1939) proposed "Penrose's Law" which purported that when the prison population would increase, the mental health population would go down proportionally and vice versa, theorizing that people simply move from one system to the next. Teplin (1984) wrote that the mentally ill are being sent to prisons in record numbers because of deinstitutionalization and the increased difficulty of having people hospitalized involuntarily.

In addition, there has been a phenomenon created called the "psychiatrization of criminal behavior" (Monahan, Davis, Hartstone & Steadman, 1983) where mental health services have expanded to include more abnormal behaviors by people who, in the past, would have been dealt with by the criminal justice system. These especially include those diagnosed with personality disorders. So, not only did the nature of jails change to include more mentally ill inmates, state hospitals also admitted more patients with criminal backgrounds. Menzies and Webster (1987) examined 571 accused individuals two years after they had been admitted to a psychiatric hospital for a pre-trial assessment. In the two-year period, 61% received a total of 663 terms of imprisonment, 49% had a total of 592 psychiatric hospitalizations and 25% spent time in both systems. Toch (1982) referred to this phenomenon as "bus therapy" where he accused correctional institutions and mental health institutions of rapidly transferring difficult-to-maintain individuals back and forth so often that the only therapy that occurred was on the bus ride between facilities. Teplin (1990) predicted that

out of one million inmates, 60,000 would have a severe mental illness and 43,000 would also have a co-occurring substance abuse problem.

Mentally ill, jail-detained individuals also appear to have several disorders, rather than just one (Abram & Teplin, 1991).

There appears to be some evidence that certain mental health problems are more likely to add to an individual's likelihood of interfacing with the criminal justice system than others. For example, major mental illness including psychosis, appears to add to an increased risk for violent behavior (Monahan, 1992). In a study of 10,000 adults, Swanson, Holzer, Ganju and Jono (1990) found that persons meeting the criteria for major depression, mania or bipolar disorder, and schizophrenia were as much as six times as likely to report engaging in violent behavior in the previous 12 months, compared to controls with no reported mental illness. The incidence was higher among those who used substances. This was further substantiated by Regier et al., (1990), who reported that 84.9% of inmates diagnosed with lifetime schizophrenia were concurrently diagnosed with lifetime alcohol disorder. This is in contrast to the general population where only one third of those with lifetime schizophrenia also reported lifetime alcoholism. In the same study, Regier et al. (1990) reported 60.9% of jail detainees with lifetime schizophrenia also had a lifetime history of drug use compared to 27.5% in the general population. This pattern was repeated with those diagnosed with bipolar illness as well. In a survey of 260 families who had a severely mentally ill family member with concurrent substance use, more than 50% reported an arrest of the family member after unsuccessful attempts to have the individual committed to a

mental health facility (McFarland, Falkner, Bloom, Hallaux, & Bray, 1989). Usually the individual was not committed to jail either because he or she was declared incompetent.

Although there is evidence that certain individuals with major mental health diagnoses are more at risk for participating in criminal behavior, there does not appear to be a causal relationship (Rice & Harris, 1997) and, in fact, few re-offend after release from a psychiatric facility. This is not the case, however, with those diagnosed with a personality disorder (especially antisocial personality disorder) or a concurrent substance abuse disorder (Hodgins, 1993). Swanson's (1990) research confirmed that individuals who had a concurrent diagnosis of alcohol abuse and a severe mental health illness were at an increased risk of committing a violent crime compared to the nonalcohol abusing population.

Ridgely, Goldman and Willenberg (1990) suggested that case management services, medication, toxicology, housing and clothing assistance, legal aid, group and individual therapy, milieu-based programs, self-help groups, and socialization are just some of the services this population requires in order to be maintained in the community. The most efficacious treatment for those dually diagnosed appears to be cognitive behavioral treatment, social skills training, behavioral contracting, relapse prevention and behaviorally oriented therapy (Miller et al., 1995), all of which can be obtained in the community with proper utilization and trained staff. Due to the type of disorders that co-occur with substance use, especially anti-social personality disorder, court mandated



treatment might increase compliancy and help prevent premature termination of treatment (Osher & Kofoed, 1989).

Risk to the community in which mentally disordered offenders are placed has been one reason opponents have raised against deinstitutionalization. There are, however, many predictive instruments available to aid in placement that would minimize the risk to the community. In addition, there are numerous community programs designed with this high-risk population in mind. New medications targeted at aggressive behaviors are also promising for maintaining severely mentally ill individuals with a propensity toward violence in the community. Lithium is one such medication that has recently been successfully utilized. It increases the rate of serotonin and appears to lower aggression (Eichelman, 1992). Some anticonvulsant medications have also been successful at diminishing explosive behaviors (Devinsky & Bear, 1984).

According to current literature, psychological problems such as anxiety, psychosis and affective disorders, even among offenders, is not predictive of future criminal behavior (Rice & Harris, 1997). A study completed in 1999 and presented at the 2001 Forensic Rights and Treatment Conference (Hartman, 1999) examined data of forensic (history of incarceration) mental health consumers and found that 50% were being maintained successfully within the community.

*Favorable Accounts: Consumers*

Although there has been a great deal of negativity reported on issues regarding deinstitutionalization it is obvious that not everyone agrees that deinstitutionalization has added to the burden of communities. Proponents pronounce that deinstitutionalization's time has come and is long overdue. They report significant gains for the mentally ill in areas of self-care, consumer satisfaction, productivity, independence and stability. One change in the last three decades is the shift from federally funded programs to state services through block grants. An article published by Carling in 1990 stated that the field of psychology and treatment of mental illness was in the midst of a "paradigm shift" where the focus on large "facility-based" thinking would be replaced by a viewpoint that acknowledged people with mental illness as service recipients or consumers. These citizens would be viewed as part of a community enjoying full membership status with simply a need for a professional support system (Stroul, 1989). In order for this to happen, numerous beneficial services needed to be put into place.

The "consumer movement" is not a new one. With early European roots it was active in the United States beginning immediately post-Civil War (Chamberlin, 1990). Known as the "consumer-survivor movement," it began in earnest with the Anti-Insane Asylum Society in Massachusetts (Geller & Harris, 1994) in the early part of the 20<sup>th</sup> century. Rekindled in the 1970s, it is very much a present day force comprised of former mental health inpatients, families and concerned others. The National Alliance for the Mentally Ill (NAMI) is an

outgrowth of this movement (Frese & Davis, 1997). Redefining the term patient to the term consumer permits more direct involvement and empowering of the individual and represents a shift toward a more efficacious and fiscally effective clinical service model (Heinssen, Levendusky, & Hunter, 1995). Building an alliance that advocates for collaboration between consumer and treatment professional helps assure greater treatment compliance (Putnam, Finney, Barkley, & Bonner, 1994).

### *Alternatives to Hospitalization*

The Office of Mental Health and Substance Abuse Services (OMHSAS) in the State of Pennsylvania developed one of the proposed solutions to the seemingly overwhelming task of surmounting the numerous obstacles to community integration. They developed a program titled, The Hospital Integration Projects Program (CHIPP) in 1991-92. CHIPP intended to advance the discharge of patients with a long-term history of hospitalization into the community. These patients have historically been the most difficult to place and had thus far been unable to be successfully supported in the community. CHIPP was designed to cultivate or build the necessary community resources to support discharge for these unique, hard to place individuals and to decrease the need for future hospitalizations. It included building a partnership between hospital and county staff, the Mental Health Association, the bureau of hospital operations, patient and consumer advocates, The Office of Mental Health and Substance Abuse Services and Pennsylvania Protection and Advocacy, Inc.

Funded by the Department of Welfare (DPW), CHIPP has placed more than 1,900 consumers in 31 counties in the state. Five counties near Philadelphia form the southeast corridor and account for approximately 600 placements. Prior to discharge, the state hospitals work in tandem with the counties where the service recipients are to be placed to plan for consumer needs. Programs are developed or accessed and supportive services are made available so that gaps in service are eliminated or reduced. In 1998-99, for the first time since its inception, DPW funded more community based services compared to state hospital services. These services included outpatient and partial hospital care, counseling, case management services, drug and alcohol treatment and crisis intervention. The intent is to continue this practice by expanding CHIPP and correspondingly decrease the number of state hospital beds. The goal is to continue to break the cycle of hospitalization and achieve full community integration for this highly vulnerable population.

Since approximately 1966, numerous studies on less restrictive treatment modalities and alternatives to long-term psychiatric hospitalization have been performed (Coursey, Ward-Alexander, & Katz, 1990). Characteristically, these studies concluded that alternative treatments were usually superior to hospitalization (Kiesler, 1982). State hospitals have spoken favorably for community treatment in part because it is typically more fiscally prudent. The model that currently is in place in Pennsylvania provides for transitional housing or residential treatment programs to provide support, supervision and treatment for newly released patients after long-term hospitalization. Usually people are

placed in these facilities while they receive supportive services to readjust to community living and to achieve increased independence. Unlike the single occupancy hotels of another era, the transitional housing sites are staffed with a combination of professional and paraprofessionals who develop and provide individualized treatment programs and structure. Although staffing may vary from site to site, there is often a contingency consisting of representation from psychiatry, psychology, social work, nursing, occupational therapy and other conjunctive rehabilitation services. Staff is trained in modeling, de-escalation techniques, anger management techniques, crisis management, problem –solving skill building and cognitive restructuring techniques. Not all services are provided on site, and the treatment team may utilize other community resources to meet the need of consumers. Often, attention is focused on vocational programs, expectations of rules that govern behavior, daily living and social skills, specialized drug and alcohol treatment, as well as community integration (Golomb & Kocsis, 1988). Treatment teams also assist linkage to financial resources and health care. Consumers are usually severely mentally ill with primary diagnoses of schizophrenia, personality disorders and bipolar illness (Coursey, Ward-Alexander & Katz, 1990).

Empirical studies of community based residential treatment programs consistently agree that these teams reduce hospital recidivism (Bond, McGrew, & Fekete, 1995). Several service characteristics have been identified as particularly effective including specificity, longitudinality and intensity (Torrey & Drake, 1994). Specificity refers to the goal of matching services to the desirable

functional change (Brekke, Long, Nesbitt & Sobel, 1997). Longitudinality refers to the need for long-term and uninterrupted services because of the chronicity of the illnesses (Bachrach, 1992). Intensity refers to the notion that more services, both in the form of quality and quantity, are better than fewer services. A study by Snowden and Clancey (1990), noted an increase in Global Assessment of Functioning (GAF) among those consumers who received more units of care at a community clinic.

There currently is little published research regarding the types of services that are most effective for maintaining a consumer with persistent severe mental illness in the community (Ryan, Sherman & Bogart, 1997). Corrigan (1991) reported that social skills training appeared to be efficacious for maintaining persons in the community. Patients themselves often report a decrease in psychotic pathology, including symptoms of bizarre language and actions, as a result of social skills training (Rice, Harris, Quinsey, & Cyr, 1990). Other social skill training that has been effective in reducing severe mental health symptomology includes teaching conversational skills, learning coping strategies, learning to recognize and reduce stress, learning to read body language and numerous additional interpersonal skills (Wallace, 1982) that lend themselves to being taught in community residential programs. Cognitive-behavioral therapy utilizing techniques of education regarding coping strategies and the building of problem-solving skills has exhibited the ability to decrease psychotic symptoms for individuals who still had residual problems resistant to medication (Tarrier, et al., 1993).

Ryan, Sherman and Judd in 1994 examined the types of services that appeared to be related to better consumer outcome. Administered by case managers, these services included community support networks, traditional psychiatric treatment, as well as rehabilitation services including vocational and educational opportunities. Building on this initial assumption, Ryan and colleagues (1997) examined data for 382 consumers using an outcome measurement of time receiving case management services prior to discharge from this type of care. The sooner they could be discharged the more successful were the services. They listed criteria for successful discharge as follows: 6 consecutive months of no hospitalization, no crisis or emergency treatment, compliance with both medical and nonmedical treatment, including taking medication as prescribed, having appropriate and stable housing, having a secure income, not having used illegal drugs or alcohol, able to demonstrate ability to meet basic needs and being ruled not a danger to self or others. Services were provided in 10 content areas: daily living skills, basic resources, mental status, medication, interpersonal, housing, income, vocational, educational, and family. Results indicated that more services were better than fewer services. The specific services that appeared to have the most positive impact on more time expedient successful community integration included those that occurred primarily in the area of community support, related to having stable housing and familial involvement. Having consistent services, rather than intermittent or inconsistent services, was positively correlated with successful discharge. Community resources to meet basic needs, early rehabilitation services that included vocational and educational

experiences also had positive impact on outcome. This study appears flawed, however, because 330 people were excluded from the study initially due to a percentage needing long-term care, being in prison, dying, being inappropriately referred for comprehensive case management services, missing, moving or refusing to comply with recommended services. The other alternative explanation might be that almost 50% of the persistently severely mentally ill are not being effectively integrated into the community no matter what services are being offered. What differentiates them from those who are utilizing services appropriately and achieving community integration?

A previously untapped treatment commodity that is offered in residential treatment programs is the relationship and influence from peers. Due to both formal and informal interactions, peers serve as powerful models. When stable and treatment advanced peers are encouraged to share with and support those who are less adjusted, many consumers experience, perhaps for the first time, the benefits of having a positive impact on the life of another individual (Heinssen et al., 1995). This can lead to improved self-concept, the building of belief in change, and the forming of long-term support networks and optimism for the future. In addition, consumers can begin the shift away from “learned helplessness” which can often be an artifact of long-term mental illness. As consumers achieve goals and move toward increasing independence, and the possibility of independent or supportive independent living, there is much growth and potential.

Increasingly there are books being written by “psychiatric survivors” that accompanies the mounting acknowledgment of the importance for persons



diagnosed with serious mental illness to participate in all levels of their care, to be included in the formulation of research studies (Carling, 1995), and to serve on boards of agencies at all levels of government (Penney, 1993). Mental health professionals, working in tandem with consumer/survivors, are developing new models of care with emphasis on housing, employment opportunities and collaborative treatment recommendations for the severely mentally ill.

Employment is a considerable facet toward achieving community integration (Bassman, 1997). A study by Gearon and Coursey (1996) noted that 54% of the consumers surveyed, cited that achieving some state of adequate and safe housing was the turning point in their recovery from mental illness. The New York State Office of Mental Health, in a survey of several thousand consumer/survivors, found that most individuals rated self-esteem, housing and having meaningful work as more important than treatment (Felton, Carpinello, Massaro, & Evans, 1996).

Quality of life issues center around freedom to make independent decisions and in having choices. Bassman (1997) wrote that without choice, personal responsibility is relinquished and therefore hope ebbs away.

Empowerment, a key element of taking charge of one's life, is defined by some mental health survivors as being connected to a community with a base of respect and participating totally in all life-affecting decisions (Fisher, 1994). Becoming active participants rather than passive receivers is accepted as being primary for continual recovery. In 1993 the Accreditation Council on Services for People with Disabilities outlined what mental health care recipients request and need which

included security, personal satisfaction, dignity and respect, decent housing and neighborhood, constitutional and individual rights, choice, personal goals, personal satisfaction, social integration and lastly, hope.

### *Role of Psychologists*

After historically being underrepresented, psychologists are progressively becoming a larger ingredient of community mental health. It is important for them to be knowledgeable about these difficult to treat patients because, with the success of initiatives such as CHIPP, these patients are increasingly part of their caseload. Services that previously included long-term hospitalizations are being replaced with both brief and intensive outpatient therapy coupled with long-term maintenance and support. Recent consumer satisfaction studies examining therapeutic effectiveness contrasted a 72% to 90% positive outpatient individual psychotherapy report to a 42% positive state hospital report (Coursey, Keller, & Farrell, 1995; Coursey, Farrell, & Zahniser, 1991). NAMI family members reported value to psychotherapy for their mentally ill relatives who utilize it at an 88% rate (Hatfield, Gearon, & Coursey, 1996).

Psychologists also continue to confront the myth that purports, “once a mental health patient, always a mental health patient.” Individuals respond to treatment and many recover fully (Harding, Zubin, & Strauss, 1987). Recovery is operationally defined as being symptom and disability free (Coursey, Alford, & Safarjan, 1997). After an exhaustive search of the recovery literature, Torrey (1995) placed recovery rates for consumers diagnosed long-term (more than 30

years post-onset) with schizophrenia at 25% for those able to achieve and maintain complete recovery; 35% for those able to maintain partial recovery, which was characterized as being greatly improved and able to live independently with minimum support, hold a job and having important and valued social relationships; 15% as exhibiting improvement but needing broad support; 10% as unimproved and 15% deceased by suicide or accident. Anthony (1993) defines recovery as more attitudinal and involving quality of life issues and the ability to attain more satisfaction in spite of limitations imposed by the disability of a significant mental illness. According to Anthony (1993), enrichment (development of self), protection of rights (equal opportunity), self-help (empowerment), basic life support (housing, meals, health care, etc.), case management (linkage to resources), treatment (symptom reduction), crisis intervention (safety) and rehabilitation (increased functioning) are listed as the critical necessary components of a successful mental health recovery oriented model.

Consistent with the belief in recovery, the American Psychological Association (APA) established a Task Force on Serious Mental Illness/Severe Emotional Disturbance that concentrates effort on issues pertaining to contact with consumers, treatment, training, and psychopharmacology to promote expertise in the profession regarding serious mental illness (Staton, 1991, Sullivan, 1995). Psychology is changing its perspective from viewing patients as pathological to one of viewing consumers' dysfunction from a competency base (Gerhart, 1990).

The practice environment for psychologists is rapidly changing. Clinicians need to be skilled in diagnostics, stabilization of symptoms, social skill building, establishing a supportive network, and active treatment. They need to be able to treat complicated patients who may have cognitive limitations, multiple serious mental health diagnoses, and current or previous substance involvement from a framework of collaboration. They need to be able to demonstrate treatment results, work with a treatment team and develop plans to keep a patient in the community. Plans that are assembled to help consumer/survivors in developing individual goals regarding housing, employment, leisure and socialization have a greater chance of succeeding if constructed in tandem with the individual, rather than only with input by a professional or relative (Carling, 1995).

Psychologists need to understand where their patients live, the make-up of their communities and the challenges consumers face living successfully in their neighborhoods. Care is often decentralized for these individuals and coordination of services may be paramount. In respect to therapy, psychologists need to be proficient in specific types of treatments that work with this consumer population. Among these are: targeted-intermittent long-term therapy, cognitive-behavioral social skills training, groups and individual psychotherapy, supportive psychotherapy, family therapy, contingent reinforcement and punishment and hierarchical training (Bedell, Hunter, & Corrigan, 1997). Therapy needs to be less intrusive and the power structure may need to be reorganized. Treatment and services need to be person centered and individualized.

Many of the former patients housed and cared for in the state hospitals now live in community treatment residential programs and in board and care homes. Numerous participate in day programs and receive case management services. Many are often estranged from their families. Paraprofessionals, under the management and supervision of psychologists, have become an important adjunct to maintaining consumers in the community, which aids in making rehabilitation more affordable. Training psychologists to meet the needs of consumers is ongoing as these facilities act as familial replacements creating all the warmth and tension of any large family complete with parental figures and substitute siblings. This provides a wealth of treatment opportunities but also requires careful and consistent evaluation, supervision and training.

### *Summary*

Opponents and proponents alike each present valid and convincing arguments regarding the success or failure of deinstitutionalization. Although there are agreements regarding some of the psychosocial variables that may exacerbate mental illness, there are also numerous incidents of divergence. There are several discrepancies between the two groups regarding who the homeless and incarcerated populations are. The opponents of deinstitutionalization blame the movement for the current homeless crisis, while the proponents argue that homelessness causes mental illness and that this problem is not a result of deinstitutionalization gone askew. While both sides agree that there are many mentally ill jail detainees, they disagree regarding whether this is directly related

to deinstitutionalization. The two opposing sides are also in agreement regarding the need for treatment for this severely mentally ill population and the need for the changing role of mental health professionals but in order to know what services are needed, it is important to first know where the people are who may be in need of services.

Fisher and Breakey (1991) note that approaches to reduce homelessness among the mentally ill are difficult to articulate because there is not awareness as to why persons become homeless or what the precursors or risk factors may be. In addition, there is usually not a comparable population available to help differentiate these variables. The popular notion that deinstitutionalization has led to burgeoning homelessness and untold numbers of incarcerations may be a myth. Once consumers' location is noted it is important to see what characteristics they may share that accounts for their stability, progress, or lack of progress, so that plans can be made to increase the chance for a positive outcome. Because psychologists figure prominently and increasingly in the equation for success, it is imperative to know and to understand this information.

The literature review, from both perspectives, overwhelmingly examined the population of homeless individuals and incarcerated mentally ill after the fact. Meaning that they examined the two conditions after the individuals became homeless or after they were jailed. This methodology is common but presents a biased outcome because it only looks at the contributing factor of mental illness and makes assumptions that ergo, if someone is severely mentally ill and is homeless or in jail it must be because he or she cannot be admitted into a state

hospital or, because he or she has a history of institutionalization in his or her background, that his or her current state is directly caused by release from the state hospital. The mitigating factors and precursors are not always extensively examined.

To remediate this one methodological flaw, it is imperative to examine the members of this particular population at the point of discharge and to follow them as they begin to live in the community. To attempt to differentiate them from the homeless or incarcerated mentally ill requires a determination of whether they truly become a part of these populations and if so, than making a determination regarding what the contributing factors were that appeared to lead up or to exacerbate these conditions.

### *Questions*

The questions that arise about the success of the CHIPP initiative and other deinstitutionalization programs have been outlined earlier in this dissertation. Although many argue that community integration is an admirable goal, and perhaps even desirable, many critics of deinstitutionalization predict that a large percentage of these patients will fail to become integrated into the community and instead will become part of the homeless population. Patients will cease receiving care and taking their medication. They will live in substandard housing and will not receive counseling. They will put the community at risk and suffer incarceration as a result. They will be victims of perpetrators and will end

up injured, deceased or infirm. They will be using substances, which will exacerbate all of the above. They will be men, rather than women. They will be African American, rather than Caucasian. They will have diagnoses ranging from psychosis to personality disorders. For the most part they will be discharged from the state hospital facility and fall through the cracks and end up wandering the streets or wasting away in some correctional facility.

Are these critics correct in their assumption or blatantly incorrect? Are long-term state hospital residents being maintained in the community? Are there psychosocial factors that protect individuals from the fate predicted by the denigrators of deinstitutionalization? Does the type of placement or level of support of placement affect outcome? Are there characteristics of the treatment team that better assure successful community integration? Does the amount of time a person was placed at a state hospital affect outcome? How about diagnosis, gender, ethnicity? Typically, the homeless population is studied from the base of homelessness, in shelters and on the street. By the time their plight is recognized and examined, they may be experiencing mental health symptoms and using substances. The same results occur for those imprisoned, who are diagnosed with mental illness. From the perspective of distress, deinstitutionalization becomes the culprit with little knowledge or understanding of the process or the etiology that led to the outcome.

This dissertation attempted to rectify the approach of looking only at the outcome and building backward to propose causative factors and instead examined what, if any factors, prior to release from a state facility, appeared to



predict or lead to the failure of this population to be integrated successfully into the community. It also examined what factors, after release, appeared to lead to a further failure to achieve maintenance within a community. Predictably, there were psychosocial factors that lead to successful community integration for an adult population released from a state hospital facility was an easily stated hypothesis but what were those factors? If these factors could be identified it stood to reason that those who did not possess these factors may be at risk for failure. Special consideration would need to be used and perhaps additional specialized services developed to increase the opportunity for successful community integration.

### *Hypotheses*

1. The greater proportion of patients released from Norristown State Hospital, as part of the CHIPPS initiative would be integrated into the community.
  - a) The whereabouts of individuals would be known.
  - b) Individuals would not be homeless (missing).
  - c) Individuals would not be incarcerated.
  
2. The greater proportion of patients who are released from Norristown State Hospital as part of the CHIPPS initiative would be in treatment. Treatment was defined as receiving psychotherapy either in the form of a day

program, individual or group therapy in the place of residence or in a clinic, and/or receiving psychiatric care in the form of medication monitoring.

3. There would be identifiable psychosocial factors that were associated with successful community integration (whereabouts known) compared with those individuals who become incarcerated or missing (whereabouts unknown).

- a) Following discharge, more women than men would be living successfully in the community.

- b) More Caucasians would be successfully living in the community compared to minority populations.

- c) Fewer individuals diagnosed with a substance abuse disorder would be living successfully in the community compared to those who have not been identified as having a substance abuse disorder.

- d) Individuals with a diagnosis of schizophrenia would be unaccounted for or incarcerated at a greater rate than those with other diagnoses, such as bipolar illness or major depression.

e). Individuals with an Axis II diagnosis would be unaccounted for or incarcerated at a greater rate than those without an Axis II diagnosis.

f). The longer an individual had been institutionalized the greater the chance their whereabouts were unknown or they were incarcerated.

g). The younger the person, the greater chance they would not be successfully integrated into the community and would instead be missing or incarcerated.

h). The type of program (including the following: LTSR-Long Term Structured Rehabilitation, Moderate Care CRR-Community Rehabilitation Residence, Maximum Care CRR, SIL-Supported Independent Living, Behavior Shaping, Psychogeriatric, ICRR-Intensive Care Rehabilitation Residence, Specialized Treatment Facility (i.e. sexual offenders), Drug and Alcohol Residential Treatment Facility) to which the individual was released would affect whether they achieved successful community integration.

- i). The location of the residence (neighborhood) to which an individual was released affected successful community integration. Neighborhood was defined by the county where the individual was placed.
- j). The more psychosocial services an individual received post discharge, the greater the chance they were successfully integrated into the community.

## Chapter 2

### Method

Data that were kept in three separate databases was included in the study. Permission to use the data was obtained from the Norristown State Hospital Internal Review Board, the Philadelphia College of Osteopathic Medicine Internal Review Board, as well as by the Pennsylvania Department of Welfare Office of Mental Health and Substance Abuse Services. Data on the CHIPPs initiative is continually collected and updated by the state of Pennsylvania (contact: Robbie Altenor, Bureau of Hospital Operations). Only one portion of the data, those which comprise the five-county region (Bucks, Chester, Montgomery, Delaware and Philadelphia) that makes up the southeastern region of the state, were utilized for the purpose of this study. In the southeast region there were 650 participants being followed in this initiative. Also, demographic data kept by Norristown State Hospital and the Health Choices Behavioral Health Program, which is the Commonwealth of Pennsylvania's mandatory managed care program, was utilized in the study.

#### *Participants*

The 650 participants included in the CHIPPs initiative in the southeast had to meet certain requirements to be included in the initiative. They were all adults

who have typically been in either Norristown State Hospital or Haverford State Hospital for longer than two years. They had numerous prior admissions to the state facility and had been unable to be maintained in the community with the current available resources. They were referred for inclusion in the CHIPPS initiative by the Norristown State Hospital treatment team or by the county Office of Mental Health liaison based on individualized requirements and meeting criteria for inclusion in new programs designed to specifically address their individualized complex needs. The CHIPPS initiative works by identifying specialized needs that can be grouped together, such as all those consumers with complex medical needs, or all those consumers with pending criminal charges, or all those consumers with addictions. The county makes a CHIPPS proposal to the state requesting permission and financing to develop personalized community residences for all consumers who have the same or similar needs. The county and the state agree to allow the county to develop a facility in a neighboring community that has a certain number of beds staffed by the appropriate persons to take care of the consumers with the specialized needs. Once the facility is operational, the patients who meet the requirements for that facility, and who the state hospital staff and county liaison agree can coexist together, were identified and released from the state hospital and those state hospital beds subsequently close. The five counties and the hospital work closely together in a collaborative effort. All 650 persons who were part of the CHIPPS initiative in this five-county region were included in the study. Only those who are not part of the initiative were excluded from the study.

## *Materials*

The data from three banks were examined and utilized. In the CHIPPs database the following information was included: name, date of birth, social security number, date of discharge from the State Hospital, the county to which they were released, the type of facility to which they were released, the county location of the residence (neighborhood), and their status (active, inactive and whereabouts known, inactive and whereabouts unknown, deceased, incarcerated). To protect patient privacy, the data collection department at Allentown State Hospital, which held and distributed the data to Norristown State Hospital, removed patients' names and social security numbers. Representatives in the department created and assigned a random identification number to each patient's data. This information was then forwarded to the researcher in Access format.

The CHIPPs initiative began in the five-county southeast-region in 1993/1994. Notes and hard copy records were kept at that time but data were not stored in an organized fashion in a database until the last two to three years. Data is reportedly kept as long as there is a need for services. In the state hospital database, the following information was included in addition to identifying information, (gender, ethnicity): diagnosis, length of stay and date of admission. The Healthchoices database included information regarding services that each participant received upon discharge.

## *Measures*

Knowing and being able to identify where an individual was living served as a measure. Were they living in the community, in jail, or were their whereabouts unknown? For the purpose of this study, living in the community was defined by where an individual received mail. This could be either living alone or with others independently, or with support in an apartment or house, living with family or friends, or living in a residential facility that was not a hospital or a correctional facility. The defining variable was that the consumer's residence could be exactly pinpointed, they had lived at this place of residence longer than 30 days, the place of residence was not deemed an emergency or temporary shelter and the consumer was not in jail. Living in jail was defined as being incarcerated in a correctional facility after being found guilty of a crime and upon sentencing by a court of law. Whereabouts unknown was defined as homelessness.

These data had been collected by the state hospital through phone checks to the directors of the residences to which each individual was discharged. This information was collected and collated every three months since discharge. It was checked against data collected by the Office of Mental Health, which oversaw each consumer upon discharge from the State Hospital. The clinical coordinator or designee from each residence filed a Resident Event form with the Office of Mental Health each time a resident eloped (away without leave), was hospitalized or jailed. This had to be done within 24 hours of each incident. When a resident returned from the event an additional Resident Event form was filed. This helped



to assure the accuracy of the data collected by the State Hospital. In addition, each resident was assigned a case manager who was also responsible for notifying the Office of Mental Health in the event a consumer left the assigned facility. Case managers stayed with consumers through all moves unless the consumer was incarcerated or became missing. Beds for consumers who were incarcerated were held for 5 days or until a determination was made that the individual would either stay in jail or return to the community. Beds were routinely held for 5 to 30 days upon an elopement, based on the prior history of an individual. If an individual had a history of elopement, beds were held longer. An empty bed held longer than 30 days due to an elopement, was assessed as “whereabouts unknown” for that resident, for the purpose of this study.

The Office of Mental Health conducted concurrent reviews approximately every 6 months, or more frequently if the consumer was deemed unstable. The purpose of the concurrent review was to assess the appropriateness of each placement and to determine whether services were meeting the needs of the consumer. The case manager, consumer, clinical coordinator and others directly involved in the care of the consumer were invited to participate in all reviews.

The paper report collected for the last two years was transferred to the database, which was utilized to correlate data for the purpose of this thesis. Successful community integration was defined as living in the community, whereabouts known for the purpose of this study. Psychosocial factors were correlated with successful community living, homelessness (whereabouts unknown) and incarceration.

### *Procedure*

Each county was responsible for following its particular consumers and giving quarterly reports to the Office of Mental Health and Substance Abuse Services (OMHSAS). In addition, consumer satisfaction teams visited all CHIPPs participants and reported to the county. The counties were responsible for relaying information to OMHSAS field offices. In addition, all providers of services were required to submit incident reports that included information such as consumer arrested, missing, hospitalized, moved, discharged, and so forth.

For the purpose of this study information was cross-referenced from the three databases. Names and all identifying information were excluded. Data were linked at all state hospitals throughout the state and was garnered through personnel employed at both Allentown State Hospital and Norristown State Hospital. Data fields were added as needed to complete the thesis. Data included the following independent variables: gender, date of birth, race, length of hospitalization, diagnoses including substance abuse, counties to which consumers were released, number and type of services they had received or are receiving. This information was collated and examined. It was correlated with the dependent variables of status and setting. Status had five parameters defined as whereabouts known, whereabouts unknown (included homelessness), incarcerated, deceased and inactive but whereabouts known. Setting referred to the type of living situation. Setting included (1) living independently or living in a family setting (living alone independently, living with others-largely independent,

living in a single occupancy hotel, living with family members), (2) living dependently (living with others-largely dependent, living alone-largely dependent supported living), (3) living in a supervised setting (including a Community Rehabilitation Residence (CRR) with minimal supervision, Personal Care Home, Specialized Personal Care Home, Enhanced Personal Care Home, Domiciliary Care or Foster Care, CRR with moderate supervision, CRR with maximum supervision, CRR with intensive maximum supervision, Drug and Alcohol Non-hospital Residential Rehabilitation, Drug and Alcohol Halfway House Program, Drug and Alcohol Non-hospital Detoxification, Mental Retardation Community Living Abode), (4) living in a Restricted Setting (Long Term Structured Residences, Crisis Respite Care, General/Veterans Administration (VA) Medical/surgical ward, Nursing Home, General/VA Psychiatric ward, Extended Acute Care Unit, State Mental Hospital, Criminal Detention, other institutional setting, Drug and Alcohol Hospital-based residential and Drug and Alcohol Hospital based Detoxification or Residential Treatment Facility for Adults), (5) homeless or place of residence unknown.

Status was extrapolated as a separate outcome and dependent variable to answer the question, “do we know where the consumer is and are they being maintained in the community”? In addition, those independent variables (psychosocial factors) that appear to lead to successful community integration (able to be maintained in the community for a period of at least 6 months-active whereabouts known) were identified.

The data was obtained over a several month period. Data was updated as additional information became available, although no new CHIPPS participants were added to the study. Applicable data was transferred from Access and reformatted into SPSS (Statistical Package for Social Scientists). A research assistant manual was created by the researcher and utilized (See Appendix) by an assistant. The assistant encoded data into SPSS. A practice-encoding run was performed with spot checks by the researcher. It was recognized earlier that some confounds would occur in this study if information was not encoded properly or if information had not been relayed properly by service providers to the county. In addition, each residential program would have individualized differences, which were not controlled for in this particular study, including level of support based on number of staff and educational level of staff. In addition, the number of crisis episodes and number of community hospitalizations an individual might have utilized was not examined. How much family contact a consumer might have had was also not assessed.

## Chapter 3

### Results

#### *Demographic Characteristics*

*Gender.* The data initially included information on six hundred and fifty (650) individuals. Of those, twenty-six (26) were found to not be part of the CHIPPS initiative and were therefore excluded from the data. The Southeastern portion of Pennsylvania represented twenty-seven percent (27%) of the entire CHIPPS program in the state and it is this data set that is reported. Of the six-hundred twenty-four (624) individuals reported, there was data for gender on 622 individuals, which represented two hundred sixty (260) females and three hundred sixty-two (362) males.

(See Frequency Table 1.)

*Age.* The ages ranged from age 22 to 84. The mean age was 50.1 years (SD=11.68). The mean age for women was 52.35 years (SD=12.81) and for men, 48.36 years (SD=10.51).

*Ethnicity.* Only 23.5% of the ethnicity data field was available, with the breakdown being 75 Caucasians (49%), 71 African Americans (46.4%), 3 (2%) Hispanics, 2 (1.3%) Asians and 2 (1.3%) Native American/other.

(See Frequency Table 2.)

Frequency Table 1.

## GENDER

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 (Female)	260	40.0	41.8	41.8
	2 (Male)	362	55.7	58.2	100.0
	Total	622	95.7	100.0	
Missing	System	28	4.3		
Total		650	100.0		

Frequency Table 2

## RACE

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 (Caucasian)	75	11.5	49.0	49.0
	2 (African American)	71	10.9	46.4	95.4
	3 (Asian)	2	.3	1.3	96.7
	4 (Hispanic)	3	.5	2.0	98.7
	5 (Other)	2	.3	1.3	100.0
	Total	153	23.5	100.0	
Missing	System	497	76.5		
Total		650	100.0		

### *Placement*

County placement included 151 individuals in Montgomery County (24.2%), 159 (25.5%) in Philadelphia County, 59 (9.5%) in Chester County, 208 (33.4%) in Delaware County and 46 (7.4%) in Bucks County, accounting for a total of 623 individuals.

### *Length of Hospitalization*

Length of placement at a state hospital before being included in the CHIPPS initiative ranged from a stay of 10 days to a stay of 18,655 days (51 years) for a female consumer who was 77. The mean length of time in a state institution was 2,275.5 days. Females stayed longer, averaging 2,356 days compared to males at 2,075.1 days. Caucasians stayed an average of 2,560 days compared to African Americans who stayed an average of 1,894 days.

### *Reporting of Hypotheses Results*

*Hypothesis 1.* The main thrust of the study was stated in Hypothesis 1. Hypothesis 1 predicted that the greater proportion of patients released from a state hospital system as part of the CHIPPS initiative would be integrated into the community, meaning that their whereabouts would be known and they would not be incarcerated or homeless. This hypothesis was supported. Of the 559 active



individuals, the whereabouts of 97.3% of nonincarcerated individuals is known.

(See Frequency Table 3.)

Frequency Table 3

## STATUS

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 (Whereabouts Known)	542	83.4	86.9	86.9
	2 (Whereabouts unknown)	8	1.2	1.3	88.1
	3 (Incarcerated)	9	1.4	1.4	89.6
	4 (Deceased)	43	6.6	6.9	96.5
	5 (Inactive)	22	3.4	3.5	100.0
	Total	624	96.0	100.0	
Missing	System	26	4.0		
Total		650	100.0		

*Hypotheses 2.* Hypothesis 2 stated that the greater proportion of patients released from Norristown State Hospital, as part of the CHIPPS initiative, would be in treatment. Treatment was defined as receiving psychotherapy either in the form of a day program, individual or group therapy in the place of residence or in a clinic and/or receiving psychiatric care in the form of medication monitoring. This hypothesis was supported.

Ninety-six percent (96%) (599 individuals) of the data was reported for the broad type of setting in which individuals currently live following discharge from the state hospital. Psychiatric and medical treatment was reported as being provided for these individuals at their place of residence. There were 415 persons (63.8%) living in a supervised setting where they received care. Supervised Setting refers to Community Rehabilitation Residences with minimum, moderate, maximum or intensive maximum supervision, Specialized, Enhanced or regular Personal Care Homes, Domiciliary Care or Foster Care, Drug and Alcohol Non-hospital Residential Rehabilitation facilities, Drug and Alcohol Halfway House Programs, Drug and Alcohol Non-hospital Detoxification Units and other residential programs. There were 101 individuals (15.5%) living in a restricted setting where they received care. Restricted settings include Long-term Structured Residences, Crisis Respite Care facilities, General or Veterans Administration Medical/Surgical wards, Nursing Homes, General /Veteran Administration Psychiatric wards, Extended Acute Care Units, State Mental Hospitals, Criminal Detention Centers, Drug and Alcohol Hospital-based Residential programs, Drug and Alcohol Hospital-based Detoxifications Units, Residential Treatment

Facilities for Adults (RTFA) and other institutional settings. There were 5.2 % of individuals, or 34 people, living in independent or family settings, which is defined as living with a related family member or living alone or with others independently or in single-room occupancy hotels. There were five individuals (.8%) living in a dependent setting which means they were living with others but were largely dependent or they were living alone with dependent supported living services, which included medical and psychiatric care. Of the group, 43 individuals (7.2%) were deceased and two persons (.3%) were known to be homeless. Of the 559 individuals for whom treatment was reported, 516 (80.1%) are receiving care. It is not known if the 34 individuals living independently were receiving care.

(See Frequency Table 4).

To further define the hypothesis stated earlier in this study regarding incarceration, some of the parameters of living setting were clarified further, revealing that in the restricted living arena, nine people (1.5 % of 623 with reported data) were incarcerated where it had been reported they received care; eight (1% of 623) were clarified as “whereabouts unknown, adding an additional six to the “known homeless” category.

The type of treatment services individuals with severe mental illness (SMI) received was obtained for the state of Pennsylvania and included data for the entire state, not just for those individuals in the CHIPPS program. It is assumed that the CHIPPS population was representative of the entire state

Frequency Table 4

## SETTING

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 (Supervised)	415	63.8	74.5	74.5
	2 (Restricted)	101	15.5	18.1	92.6
	3 (Independent/ Family)	34	5.2	6.1	98.7
	4 (Dependent)	5	.8	.9	99.6
	5 (Homeless)	2	.3	.4	100.0
	Total	557	85.7	100.0	
Missing	System	93	14.3		
Total		650	100.0		

population who received state funded psychiatric/medical services. Data were only recorded for those individuals who had medical/psychiatric services provided by the state. The SMI population included those individuals who did or did not have a coexisting medical condition. Only primary diagnoses were recorded. The population included 38.1% individuals diagnosed with Schizophrenia (295.xx), 43.2% diagnosed with Bipolar/Major Depressive Disorder (296.xx), 2.9% diagnosed with Psychotic Disorder (298.9x), .2% of individuals with a primary diagnosis of Borderline Personality Disorder (301.83) and 15.5% with a diagnosis of other.

The state also reported a treatment history in the past year for 66.3% of individuals in a priority group (those with a major SMI (295.xx, 296.xx, 298.9, or 301.83) sufficient to result in functional impairment that interferes or limits significantly one or more major life activities) and for 7.2% individuals who meet the criteria for SMI but do not meet all of the criteria of the priority population. Utilization of treatment services for the state included 18% of the individuals who had one or more psychiatric inpatient admission dates with a cumulative length of stay greater than or equal to 10 days, 17% of individuals who utilized partial hospitalization encounters with cumulative hours greater than or equal to 30, 34% who utilized case management services with cumulative quarter hour usage greater than or equal to 30, 4% who utilized crisis services at least once and 5% who utilized Clozapine support services. Services also overlapped and were not mutually exclusive. Eighty-one percent of individuals meeting the criteria of SMI

were considered continuous users, meaning that they had an encounter date of service at least one month within every three months.

*Hypothesis 3.* Hypothesis 3 stated there would be identifiable psychosocial variables associated with successful community integration (whereabouts known) compared with those individuals who became incarcerated or were missing (whereabouts unknown). The hypothesis was not supported. Utilizing Pearson's correlation to examine gender and status revealed no significance. Women were not more successful than men at living in the community. Of the eight individuals for whom it was reported that their whereabouts were unknown, four were females and four were males. Of the nine individuals incarcerated, seven (out of 313 for whom both gender and status were reported) were males and two (out of 226 for whom both gender and status were reported) were females. Pearson's correlation was also utilized to examine if ethnicity was related to rate of successful community integration, again without significance. Unfortunately ethnicity was not reported for those whose whereabouts were unknown. For those incarcerated, ethnicity data were only available for three. Two were Caucasian and one was African American. The data regarding substance abuse and diagnosis for the population reported was incomplete preventing these variables from being examined more fully. Length of time institutionalized and age, were not found to be related to success of community integration utilizing Pearson's correlation as well as a chi-square analysis. The results were the same for the type of program to which people were released and the county location. The exact number and type

of psychosocial services individuals received were not reported, only whether they were receiving services.

Of the population of incarcerated individuals (nine), 67% of them were discharged to Philadelphia County. A chi-square analysis did not prove significant for county of placement when related to rate of incarceration, which may have been due to the small "n." An examination of what county (neighborhood) appeared to have the least restrictive housing (supervised, independent family) was significant for Montgomery County, utilizing Pearson's correlation. It was significant at alpha level .05,  $p = .024$ . It is unknown why this county appeared to have more residents living in congregate sites that were labeled as less restrictive. This factor would need to be examined more fully. It could be that residents released to this placement had less severe conditions or perhaps it was simply related to governmental decisions regarding the type of housing made available in this locale. It was not possible to determine if one type of residence was more successful in keeping an individual from becoming homeless or from being incarcerated because the initial discharge residence was not recorded in the database, only the current residence. (See Table 5)



**Table 5**                      **Correlations**

		<b>SETTING</b>	<b>COUNTYPL</b>
<b>SETTING</b>	<b>Pearson Correlation</b>	1.000	.095(*)
	<b>Sig. (2-tailed)</b>	.	.024
	<b>N</b>	557	557
<b>COUNTYPL</b>	<b>Pearson Correlation</b>	.095(*)	1.000
	<b>Sig. (2-tailed)</b>	.024	.
	<b>N</b>	557	624
* Correlation is significant at the 0.05 level (2-tailed).			

## Chapter 4

### Discussion

The CHIPPS initiative in the state of Pennsylvania was begun in 1991-1992. Since that time, 2,170 state institutional beds have been closed. The southeastern portion of the state represents 27% of those beds. In addition, the data from this region is very representational of other regions in the state. For example, only 23 total participants have been incarcerated statewide, with 9 of those located in the southeastern region; 198 participants are deceased with 43 of them representing the southeast. The total dollars diverted from Pennsylvania state hospitals to community-based mental health services is more than \$155,126,913.00. So, the question is, does it work? That was the entire premise of this dissertation.

“The objectives of the CHIPPS initiative were outlined by the creators and included (Altenor, 2003) the following:

- 1) The promotion and the discharge of patients with long-term histories of hospitalization.
- 2) The promotion and the discharge of patients with complex service or treatment needs.
- 3) The building and strengthening of community-based services for people who have severe and persistent mental illness.
- 4) To build capacity for diversion services intended to promote alternatives to hospitalization in the state-operated psychiatric hospitals.”

According to the data, it would appear that the objectives have been reached. The CHIPPS initiative is placing consumers in the community and the majority of them are remaining there. They are not becoming homeless, they are not going to jail, their whereabouts are known and they are remaining in treatment. This is happening regardless of individual psychosocial factors such as gender, age, race, length of institutionalization, type of residential program or location of residence. This is what the data tells us. So, what does it mean?

It means that we, as a society, have come a great distance since the early days when the mentally ill were kept hidden in a back room behind locked doors or were placed in an asylum or an institution for life. Consumers are being mainstreamed into the very fabric of everyday life. They are in your neighborhood and in mine. They are not committing crimes or adding to the homeless burden but are remaining in treatment and surviving and thriving right next door.

### *Theoretical implications*

*Homelessness.* The current premise and often-reported saga of homelessness needs to be re-examined. "Our Way Home: A Blueprint to End Homelessness in Philadelphia," published by the Greater Philadelphia Urban Affairs Coalition (1998) stated in it's treatise that to end homelessness society needs to address the failure of deinstitutionalization for persons with SMI. The

results of this dissertation research and the research of others would caution those involved with concentrating on the homeless population from making such global statements. The homeless problem is certainly complex and many persons who are homeless have mental health difficulties but these may not be the individuals who were part of the deinstitutionalization movement. Toro (1998), in an examination of the homeless literature, reported that the homeless with schizophrenia account for less than 10% of those with mental illness while those with Post Traumatic Stress Disorder (PTSD) account for approximately 40%. In this dissertation the greater percentage of persons deinstitutionalized as a result of the CHIPPS initiative were schizophrenic. It may well be that it is homeless condition itself that is partly the cause for mental illness and perhaps the violence so often associated with it.

Goldman and Gattozzi (1988) cite the loss of income due to the termination of Social Security Income (SSI) and Social Security Disability Income (SSDI) in the 1970s and 1980s as partly responsible for the homeless problem, insinuating that poverty is more to blame. Jacob, Newman and Burns (2001) also blame poverty, stating that proper assessment of homeless individuals with mental illness would allow many to collect social security benefits. Still others cite the “drift down phenomenon (Benda, 1987) crystallizing the complexity of the homeless problem. They argue that it is the fault of inadequate housing, inadequate employment, mental illness, early prison release, extreme poverty and substance abuse among other factors. Breakly and Fisher (1990) stated that homelessness is the result of inadequate income support for the poor,

coupled with the paucity of affordable low-income housing. Obviously the reasons and the solutions for homelessness are intricate but it would appear that those released from the state hospitals under the CHIPPS initiative are not the reason for the mushrooming homeless population.

To better address and answer the questions regarding the homeless population will require new theories to be developed or built upon. Society can no longer simply blame deinstitutionalization for this critical state. New reasons need to be sought and tested and old rationales need to be re-examined. No one disputes the fact that there are many homeless individuals who have mental illness. We need to ask ourselves, how did this happen? Did this occur due to the stress of homelessness or did the circumstances that led to homelessness contribute to the development of mental illness? Is it simply that individuals who lead marginal existences due to mental illness are not able to access existing services and, therefore, their condition becomes exacerbated; or is it due to the cost or availability of medication and treatment? Are these services even available in the neighborhoods where those most vulnerable to becoming homeless live? Do we even know who is most vulnerable? Is time a factor? Is someone more vulnerable to becoming mentally ill the longer they are homeless? The questions and direction for building new theories regarding the mentally ill homeless are endless. So are the questions about another vulnerable population, those who are severely mentally ill and jailed.

*Incarceration.* The overcrowding of prisons cannot simply be blamed on deinstitutionalization. Although this study did not have a significant effect for incarceration, it was noted that of the five counties where individuals were released, a total of nine (67%) previously deinstitutionalized individuals were incarcerated in Philadelphia County. This would need to be examined more fully but one suspects that the reasons may simply be the geographical size of the county, the size of the population or the fact that there are more prisons located in this area.

Although this dissertation did not find a linkage between deinstitutionalization and incarceration, no one would argue that there are substantial numbers of persons with mental illness in jail. The incarceration of mentally ill offenders remains controversial but the scope of the problem is difficult to analyze and predict. Rice and Harris (1997) noted that the scope of mental health treatment has expanded to include additional forms of deviant behavior; and where once these individuals would have been seen exclusively in the criminal justice system, they are now included in the total number of those incarcerated with mental health diagnoses. In addition the term “mentally ill offender” is often influenced by legal and political concerns as it is by mental health considerations (Rice & Harris, 1997).

Mental health professionals need to continue to understand this population and seek alternatives to jail for the severely mentally ill who participate in criminal acts or offend against others. There needs to be a better understanding of the breakdown in the psyche that may cause individuals to lose touch with a

reality that may lead them into criminal acts. There needs to be better monitoring and control before incidents occur. Additionally, better treatment is needed while mentally ill offenders are incarcerated, and adequate resources need to be put into place to maintain them in the community upon discharge. Non-compliance issues need to be examined and treatment modified to better address this issue. The psychology profession needs to learn what percentage of mentally ill individuals who become incarcerated have stopped taking their medication or prematurely ended treatment prior to arrest. Substance abuse as it relates to mental illness needs to be better understood as well.

According to a study presented at the 13<sup>th</sup> Annual Conference on State Mental Health Agency Services, Research, Program Evaluation and Policy: Developing an Evidence-Based Culture to Reform Systems, Jakuba, Pandiani, Simon, Banks and Goessel (2003) reported that persons who receive mental health services were more likely to interface with the criminal justice system if they had a co-occurring substance abuse problem compared to those consumers who received mental health services without a co-occurring disorder. This was true regardless of gender, age or race. This was the case in Pennsylvania, Vermont, Florida and elsewhere. Perhaps it is substance abuse that is the main factor that causes a specific population of severely mentally ill individuals to commit offenses. Would this mean that mental illness, without a co-occurring disorder, does not lead to incarceration? This theory needs to be examined more fully.

### *Practical Implications*

According to this dissertation, it would appear that the majority of the deinstitutionalized population is not homeless and not incarcerated. They are living in numerous small and large facilities in the community. So, how do these facts impact treatment professionals?

*Service Delivery.* Having the more severely mentally ill in the community means that the manner in which psychologists and other mental health professionals deliver services has changed. The services themselves have changed, along with the location of service delivery. Treating the severely mentally ill in the community means that the places where mental health practitioner internships are located have changed, as well as the type of patient treated. It ultimately means that schools that educate mental health practitioners have to change to teach about working with the SMI patient in the community. They may also have to teach about recovery when they used to teach about maintenance. It means that the concept of recovery has to be rethought and perhaps redefined.

Community Mental Health Treatment is not a new idea. It has its roots in the work performed by Dorothea Lynde Dix (1802-1887) who initiated transferring those with severe mental illness out of asylums and jails making communities responsible for their continual care (Shore, 1992). Many of them were placed into hospital settings, however, which still provided the community



with a layer of insulation from needing to interact with the mentally ill population. With the post World War II movement, however, the advent of deinstitutionalization took the early work of Dorothea Dix to the current level. The current level in the State of Pennsylvania has resulted in more than 2,000 persons being discharged into the community in the last decade alone. The majority of the discharges nationwide have been to Community Support Programs (CSPs), which are psychosocial rehabilitation programs based in the community with the specific purpose of housing and providing treatment for the chronically mentally ill (National Institute of Mental Health [NIMH], 1982). The programs vary in type, number of persons housed, organization, type of services offered and qualifications of staffing. Although it would be surmised that some are better than others, it appears that overall they are succeeding in keeping the chronic, severely mentally ill in the community and at the same time are reducing hospital recidivism (Bond, et al., 1995). This is where treatment is occurring. In these residences and in neighborhood clinics, partial hospital settings, primary care physicians' offices and private homes. This is occurring as the topic of deinstitutionalization is addressed and perhaps put to rest while at the same time a new vernacular is forming, one of recovery; recovery from SMI.

*Recovery.* Recovery and mental illness were not usually seen in the same sentence. With the advent of deinstitutionalization and the reasons that led up to it, recovery also seems within our grasp. Interestingly the first step may be living in the community and feeling a part of the world, having a sense of belonging. A

national report on system performance indicators (Onken, Dumont, Ridgeway, Dornan, & Ralph, 2002) has set the task of discovering what factors lead to recovery. By developing and identifying mental health system performance measures, it is hoped that the next step toward community integration will be an inclusion of the concept of recovery and the recognition of individuals with SMI as persons with chronic manageable disorders that live life as fully and richly as someone without SMI.

This dissertation answered basic questions for a select population but raised many more. It seems certain that society will never go back to hiding or marginalizing a very vulnerable population; but we still lag far behind in our understanding and treatment of mental illness, as well as in mainstreaming and truly integrating the chronically severely mentally ill. It would appear that deinstitutionalization is at least one small step in the right direction.

### *Limitations of the Study*

Every planned study has limitations and although the experimenter would prefer to know them in advance it is not always possible. In the design there were several factors that were knowingly not controlled. The use of archived data was dependent upon the accuracy of the collection and the recording. Accuracy was assumed and was not double-checked. This data was then transformed to a separate research database. There could have been errors in that encoding. Random checks were completed but may have been insufficient.

There were parameters of the independent variables that were not controlled. Some of these are the fact that the broad category of service was looked at and quantified but not the specificity of the services. Specificity refers to medication variables, type of treatment, level of participation in treatment, level of education of treatment providers, location of treatment programs and numerous additional treatment factors that were not controlled and would need to be examined in future research endeavors.

The broad category of living status produced large groupings of type of residence (e.g. supervised, restricted). There would be vast differences in the type of residences in each category that were not examined or controlled. In each residence there would be numerous variables that could account for success in maintaining an individual in that community that were not controlled (e.g. how many residents lived there, what were the demographics of residents, staffing level).

Neighborhood variables that may affect an individual were not examined, just the location defined by county was given. Socioeconomic factors that may be related to outcome were also not examined in this study since because it is assumed that aftercare plans for every person released under the CHIPPS initiative included the level of care needed for successful integration for each person irrespective of ability to pay or ability to access services.

Individual differences other than what are listed among the predictor variables were also not taken into account in this study. Among these are whether an individual has contacts with his or her family or how long he or she has been

diagnosed as mentally ill. The only persons being included in the study are called by the state “the hardest to place.” They may present a much different picture from those individuals released from the state hospital who are not part of the CHIPPS initiative. Another study may include comparing individuals released from the State Hospital as part of deinstitutionalization with those released under the CHIPPS initiative.

In addition, the level of the dependent variable labeled whereabouts unknown, and assumed homeless, may be inaccurate because an individual may have left the vicinity and living with a person unknown to the state. Whereabouts unknown as a measure of poor integration has other flaws in that an individual’s status may have more to do with the follow-up process than with their level of functionality and assumed vulnerability. They may in actuality represent increased functionality, which therefore permitted them to be more mobile. The measure whereabouts unknown can be very complex and follow-up studies would need to introduce another measure to rate degrees of successful integration. For the purpose of this study, it simply serves as a baseline measure in an attempt to begin to understand how, and if, individuals are being adequately monitored and served in their communities.

Another study needs to look at treatment factors in successful community integration. The utilization of demographic and diagnostic factors as predictor variables in this study serves as simply the starting place to begin to understand if this patient sect mirrors the data of other patient sects. This population is unique in that it represents the most difficult to place, are presumed to be the most

severely ill, and who, therefore received individually designed programming to hopefully increase the rate for success. In order to compare this population with another, it is first important to know if it is indeed representative of the mentally ill population at large. If in fact it mirrors extant populations, then the data may need to be weighted to adequately represent statistical differences.

No study can examine all facets and can only be a very small piece in a long strand that ultimately leads to a better understanding of a very complex issue. This study is no exception and only seeks to provide a snapshot and a starting block to subsequent research. In addition to all of the above-mentioned limitations of this study, the statistics themselves will be subject to Type I and Type II errors and this will be compounded due to the multivariables. It is noted also that data on the CHIPPs patients is constantly updated at Norristown State Hospital as new information becomes available. Even though the researcher was frequently apprised as new updated information became available, it is possible that even the data set reported in this dissertation is not absolutely current.

### *Future Directions*

To truly answer the question, “does deinstitutionalization work,” we have to look beyond the basics of where these individuals are living. Although it would appear that community integration is succeeding, the parameters of this dissertation did not look at what constituted success. The first step in attempting to examine success requires knowing where individuals who were previously

institutionalized are living and if they are remaining in the community. That was the topic of this study. That is only the most rudimentary variable of success, however. The word integration implies that not only are individuals residing in the community, but that they are interacting with it in a positive manner. This study did not examine the factor of interaction. It would require defining positive interaction followed by an attempt to measure it. One would assume that if a person is engaged in treatment, they are having a positive interaction but if this is the extent of their interaction perhaps it is not enough. Future research would need to answer these questions before society can truly say that the formally institutionalized severely chronically mentally ill have been integrated into the community. What we do know is that they are able to successfully live outside the protected setting of a state institute within residences in communities.

This study did not examine differences in residences, though, and attempt to define and quantify them. It is not known if the restricted residences are any less restrictive than the former hospital setting. It is not known if the residences promote a degree of independence and are representative of what the population at large may experience. It is not known how they themselves fit into and participate in community interactions. The type of treatment provided also needs to be examined. What type of treatment are people receiving and what is the goal? Is it a reasonable goal to move residents toward independent housing? All of these factors need to be examined before one can truly say that deinstitutionalization has been successful. A bigger societal question would be: Is there even enough affordable housing for everyone who needs it?

The number of hospitalizations following discharge was not examined in this study. It could be argued that not living in an institution is preferable to even numerous hospitalizations following discharge. But is it? Is it more cost effective and less stressful on the individual? These questions would need to be explored further before the success of deinstitutionalization is touted.

Quality of life issues were also not explored. Quality of life needs would include not only residential environment, treatment and socialization but vocational, independence, educational and economic needs as well. It would include subjective measures that allowed for a capacity for individuality in meeting ones own needs. Consumers reported wanting to live in “normal housing” with flexible supports (Carling, 1990). This would be another reason to examine the availability of affordable housing. The success of community integration is more than numbers, it is the subjective experience of consumers and whether they feel they can hope, dream and build toward a productive and meaningful future.

This study examined a select population. It looked at data for those individuals deemed to be the most ill and the most difficult to place. This population had residences and programs specifically designed for them. They were released into residences where they were thought to be compatible with the existing consumers already living there. Another study would need to examine the general population of released individuals to ascertain if they did as well. The non-CHIPPS consumers have not been followed as closely or in the same way.

They may have faced additional difficulty in achieving independence and community inclusion.

Treatment types would need to be examined additionally in another study. Just simply keeping individuals in treatment is not sufficient. Just keeping people maintained is not sufficient. Treatment efficacy needs to be examined and questions answered such as, are people actively participating, are they taking their medication, have medication doses been altered and decreased, are they meeting their treatment goals? In addition it would be surmised that more persons with SMI are being seen in primary care physicians offices. Are the physicians adequately trained to work with this population? What is the quality of care provided? The journey to answer these and the earlier questions is only just beginning.

The full impact of deinstitutionalization is only just beginning as well. The dark days of unlimited and indefinite institutionalization appear to be over. Professionals and patients alike dare to dream of full recovery. Many of the conscientious objectors credited with beginning the deinstitutionalization movement are no longer living, but they left behind a proud legacy of hope for a bright future for everyone, including those labeled as hopelessly insane just a few brief years ago.



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## Appendix

### Research Assistant Manual

Data for the Community Integration and Normalization Dissertation must follow IRB guidelines exactly. The research assistant must maintain the strictest confidentiality and adhere to the most stringent of clinical ethics throughout the entire process from first site of the information, through the encoding process, during the analysis of the data and upon completion of the project. There must not be a Master list. All names and identifiers (e.g. social security numbers) must be stricken from the data and all attempts must be made to protect the identity of any and all individuals who have information subsumed in the databases. Robbie Altener, RN, MSN, Clinical Specialist for the Bureau of Hospital Operations at Norristown State Hospital will control the data. Upon completion of the project all data will either be returned to the State Hospital or destroyed via shredding.

Information will be obtained and encoded in the following fashion:

1. A practice encoding run will be performed prior to actual data encoding.
2. SPSS will be the statistical software utilized in the encoding and in the analysis of the data.

3. The software will be installed and data will be loaded on only one computer with one disk back-up.
4. Back-up will be completed each day that data is encoded into the computer.
5. The back-up disk will be kept in a locked file cabinet and the computer must be password protected.
6. The researcher will be prohibited from viewing the data prior to the running of the analysis except for approximately five percent that will be randomly selected for the researcher to spot check accuracy of encoding.
7. Variables will be explained in depth prior to encoding so that the Research Assistant will understand how to properly encode data, which may seem confusing or nebulous. The research assistant will verify any nebulous data with the researcher prior to encoding.
7. Dependent variables will be encoded in the following manner:
  - a). Dependent Variable: "Whereabouts Known" = 1.
  - b). Dependent Variable: "Whereabouts Unknown" = 2.
  - c). Dependent Variable: "Incarcerated" = 3.
  - d). Dependent Variable: "Deceased" = 4.
  - e). Dependent Variable: "Inactive-whereabouts unknown" = 5.The dependent variables will be coded under the SPSS heading: 'Setting'.
8. Independent Variables will be encoded in the following manner:



- a). Independent Variable, Gender (SPSS heading): Female = 1, Male = 2.
- b). Independent Variable, Age: (SPSS heading): extrapolate from date of birth and record actual age.
- c). Independent Variable, ethnicity: (SPSS heading): Caucasian = 1, African American = 2, Asian = 3, Hispanic = 4, Other = 5.
- d). Independent Variable, history of substance abuse (hx. SA) (SPSS heading): hx. = 1, no hx. = 2.
- e). Independent Variable, Treatment (Rx.) (SPSS heading): In Rx. =1, Not in Rx. = 2.
- f). Independent Variable, Axis I. Diagnosis (1DX) (SPSS heading): Schizophrenia = 1, Major Depression/Bipolar =2, Psychotic Disorder = 3, Borderline Personality Disorder = 4, Other= 5.
- g). Independent Variable, Length of Time in the State Hospital (LOS) (SPSS heading): Record actual days.
- h). Independent Variable, Discharged to what county (County) (SPSS heading): Montgomery = 1, Philadelphia = 2, Chester County = 3, Delaware County = 4, Bucks County = 5.
- i). Independent Variable: Type of Care (Status) (SPSS heading): Supervised = 1, Restricted = 2, Independent/Family = 3, Dependent = 4, Homeless/Unknown = 5.