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The Impact of Deinstitutionalization on Individual Who Receive Services from Guild Incorporated

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THE IMPACT OF DEINSTITUTIONALIZATION ON INDIVIDUALS WHO RECEIVE SERVICES FROM GUILD INCORPORATED

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CERTIFICATE OF APPROVAL

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ABSTRACT

FROM INSTITUTIONALIZATION TO INDEPENDENT LIVING: A STUDY OF THE IMPACT OF DEINSTITUTIONALIZATION ON INDIVIDUALS RECEIVING SERVICES FROM GUILD INCORPORATED

MEREDITH K. FOSTER

The purpose of this qualitative study is to gain a deeper understanding of the impact that deinstitutionalization has had on individuals who receive case management services from Guild Incorporated. Participants will be gathered for the qualitative portion using a non-probability sample, and identified by a professional within the agency. Research for this portion was conducted through an in-depth interview where participants were asked to describe the impact that deinstitutionalization has had in their lives. Results for this study show that individuals who moved out of Guild Hall initially felt fear and helplessness, loss of support, and financial burden after moving to independent living. Community supports, finding structure and planned social activities helped with the transition. All participants expressed satisfaction with their current living arrangement and preferred independent living to institutionalization. Implications for social work practice and policy are discussed.

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CHAPTER 1: INTRODUCTION

Background of Problem

This research focuses on the impact of case management on deinstitutionalization of Guild Hall. This deinstitutionalization occurred in the 1990s. This deinstitutionalization is considered to be the "second wave" of deinstitutionalization because Guild Hall was created in response to the deinstitutionalization of the large state hospitals in the 1960s. The 100 bed institution provided treatment and resources for individuals with serious and persistent mental illness to live in a community setting. In 1994 Guild Hall closed and moved most former residents into independent living situations such as an apartment. The purpose of the research is to provide an understanding of the deinstitutionalization process on individuals who moved out of Guild Hall and who continue to receive case management services from Guild Incorporated.

Statement of the Problem

This research study addresses the question of what it is like for individuals with serious and persistent mental illness to move out of large institutions and how this has impacted their lives. The purpose and significance of the research study is to describe the lived experiences of individuals who moved out of Guild Hall and continue to receive services from Guild Incorporated. While researching the area of deinstitutionalization, many theories are found addressing the impact of deinstitutionalization on individuals with a serious and persistent mental illness. The

theories include Systems Theory, Strengths Perspective, Assertive Community Treatment, and Supported Housing. These theories will be explored while addressing the experiences of individuals whom moved out of a large institution. Furthermore, how the experiences have impacted the lives of the individuals will be explored.

Research Question

Specifically, this research study will ask: what is the impact of deinstitutionalization on individuals who moved out of Guild Hall and continue to receive services from Guild Incorporated? The actual questions asked of participants are included in Appendix C.

Summary

There is much research in existence on the impact of the deinstitutionalization of large state hospitals. However, there is little research on the deinstitutionalization of smaller institutions which occurred in the mid 1990s. However, little research exists on "the second wave" of deinstitutionalization when smaller institutions closed. Most of these individuals who left the institutions moved out into their own housing in the community with mental health services in place such as case management, supported housing services, public health nurses, and outpatient psychiatrists. In most cases this can be considered a successful deinstitutionalization because most individuals continue to maintain independent living. Nevertheless little research exists on "the second wave" of deinstitutionalization and the impact that the closing of Guild Hall has had on individuals has never been researched.

This chapter addresses the background of the deinstitutionalization of Guild Hall. The following chapter will include a discussion of the existing literature on

deinstitutionalization. Next, chapter three will discuss the theoretical framework of deinstitutionation. In chapter four the methodology used in this study is presented. Chapter five will present findings of this qualitative study. In the final chapter, Chapter six discusses areas of limitations and implications for future studies.

CHAPTER 2: LITERATURE REVIEW

Introduction

The following section will provide a review of the literature on the impact that deinstitutionalization has on the lives of individuals with a serious and persistent mental illness. The literature review will begin with a historical perspective and motivational factors behind deinstitutionalization. The review will also contain information about Guild Incorporated, which deinstitutionalized in 1994. This section will summarize with conclusions drawn from the review. Finally, gaps in the literature will be discussed and the review will be summarized.

Definitions of Terms

For the purpose of this study, the following terms are operationally defined:

Serious and Persistent Mental Illness

According to the Minnesota Comprehensive Adult Mental Health Act (1998), for the proposes of case management, a person with serious and persistent mental illness is an adult over the age of 18 who has a mental illness and meets at least one of the following criteria:

1) the adult has undergone two or more episodes of inpatient care for a mental illness within the preceding 24 months;
2) the adult has experienced a continuous psychiatric hospitalization or residential treatment exceeding six months duration within the preceding 12 months;
3) the adult:
    a) has a diagnosis of schizophrenia, bipolar disorder, major depression, or borderline personality disorder
    b) indicated a significant impairment in functioning; and

c) has a written opinion from a mental health professional in the last three years, stating that the adult is reasonably likely to have future episodes requiring inpatient or residential treatment of a frequency described in clause 1) or 2), unless ongoing case management or community support services are provided.

4) the adult has in the last three years been committed by a court as a mentally ill person, under 243B or the adult's commitment has been stayed or continued; or

5) the adult: was eligible under clauses 1) to 4), but the specified time period has expired, or the adult was eligible as a child under section 245.4871, subdivision 6.

Deinstitutionalization

Deinstitutionalization is best defined by a 1977 United States General Accounting Office report.

> *The process of preventing both unnecessary admission to and retention in institutions; finding and developing appropriate alternatives in the community for housing, treatment, training, education, and rehabilitation of [persons] who do not need to be in institutions, improving conditions, care, and treatment for those who need to have institutional care. The approach is based on the principle that persons are entitled to live in the least restrictive environment necessary and lead lives as normally and independently as they can (p. 1).*

Case Management

Bachrach (1998) provides the classic definition of case management. According to this definition case management should include the following components:

1) providing assistance to the individual with accessing appropriate health services
2) helping the individual develop basic living skills
3) vigorous outreach
4) practical help rather than "therapy"
5) improvement of the individual's quality of life
6) clinical intervention when required

Deintstitutionalization

Historical Perspective The longest running response to mental illness in America is to hospitalize and segregate the most severely affected people (Sullivan, 1992). Scull (1977) talked about institutions as a convenient way to get rid of inconvenient people. Historically, institutions were seen as a way to protect individuals from mental illness and the community from each other (Sullivan, 1992)

Within the past 45 years the asylum has not been seen as a final destination for individuals with serious and persistent mental illness. Deinstitutionalization was motivated by several factors beginning with the advent in the 1950s of psychotropic medications, which allowed enough symptom management that deinstitutionalization was possible. Another factor was the desire to offer better treatment and a better quality of life for people with a mental illness (Johnson, 1990). Many individuals in asylums were regressed and dependent. They often exhibited apathy and withdrawal. This problem was blamed on institunalization. However, now some experts believe that in some cases it may have been the result of the negative symptoms of schizophrenia (Dawber, 1997).

Contributing Factors The political and cultural upheaval of the 1960s gave rise to many changes in attitudes and philosophy that contributed to deinstitutionalization. One of these was a shift toward the empowerment of local communities rather than large institutions. Attention to civil rights, including the rights of individuals with mental illness, led to legislation making it more difficult to force someone to receive treatment against his or her will. Other contributing legal issues included the right to treatment, the right to refuse treatment, the right to protection from harm, the right to decent living conditions, and the right to the least restrictive environment needed for care (Johnson, 1997).

Finally, a major factor in deinstitutionalization was the fact that it would save the states money. Deinstitutionalization was seen as a way to decrease the need for costly state hospitals and therefore was eagerly embraced by state government. States benefited from discharging people to the community because most of them went to nursing homes, board and care homes, or other residential alternatives supported with federal, local, or private funds. Furthermore, in 1963 individuals with mental illness became eligible for Supplemental Security Income from the federal government. This provided some financial ability to live in the community and further relieved the states of many of the expenses associated with caring for individuals who have a mental illness (Holley, Hodges, & Jeffers, 1998).

By the 1970s researchers were beginning to recognize that some sections of inner cities were starting to resemble inpatient psychiatric units. Thus, although technically free from restraint, individuals with mental illness still remained excluded from normal social process. This resulted in the development of the community

support services concept. The community support system represented a conceptualization of the variety of needs and services that individuals with mental illness require to live successfully in the community (Holley, et al., 1998). Guild Incorporated eventually became one of these community supports.

Guild Incorporated

Agency History

Guild Supported Housing Services (GSHS) is one of three Guild Incorporated program sites. The agency's roots date back to 1906 when women from various St. Paul parishes came together to form The Guild of Catholic Women (GCW). The GCW was created out of a commitment to community service and a promise to help those most in need. In its infancy GCW offered services to new immigrants. In 1912, they provided housing for young working women (GCW Brochure, 1996).

In 1966, the GCW build a large residence hall, which was located at 286 Marshall Avenue in St. Paul. It was originally used as a home for working women. However, as stated above, by the early 1970's, state hospitals serving persons with mental illness were closing. As a result, many people were left without a place to live. The GCW responded to this need and opened the doors of the residence hall to adults with mental illness (GCW Brochure, 1996).

In 1990 Guild Incorporated shifted away from the institutional model in favor of a supported housing using a strengths perspective. This called for the agency to help individuals to establish their own homes, by providing on-going services as needed to help the individual maintain his or her housing and live successfully in the community. The rationale that motivated the agency was to provide highly

personalized, flexible support services, which would be available when and where needed. All of this focused on the preferences and goals of the individual (GCW Brochure, 1996).

In 1994, Guild Incorporated coordinated with Ramsey County to convert the facility-based program into a community-based service known as Guild Supported Housing Services (GSHS). As a result of this conversion most individuals moved from the facility into their own apartments. Funds that had been used to maintain the residence were converted into rent subsidies to help make housing affordable. In 1998, GSHS contracted with Ramsey County to provide intensive case management services to its clients which includes smaller case loads and more frequent client and case manager contact (GCW Brochure, 1996).

Guild Supported Housing Services

"Helping people with mental illness lead quality lives" is more than just a mission statement at GSHS. It is the foundation of all services provided. It is also the philosophy that motivates staff to provide services for more than 140 adults. GSHS provides intensive case management to individuals who are residents of Ramsey County, and have been diagnosed as having a serious and persistent mental illness (GSHS Mission Statement, 1999).

According to the agency, getting the right kind of help at the right time is the key to recovery (GSHS Brochure, 1998). Through GSHS, individuals receive services whenever needed. Help is provided to individuals in their home or out in the community. Services in the community may include trips to the grocery store, doctor's appointments, or assistance with the public transportation system. Even if the

individual's housing changes, services continue. For example, if a person is hospitalized, GSHS may help the keep client from losing his or her housing and/or employment. Case managers will also advocate for the individual while hospitalized by making recommendations with the hospital staff about his or her treatment such as information about the individual's behavioral baseline as well as successful versus unsuccessful treatment approaches.

GSHS case managers help each client access the services and opportunities which they want and need. Case managers work primarily with people who have intensive needs and require more frequent contact in order to maintain independent living. Case managers and nurses work in teams to better serve the clients. Each team consists of five or six members, which includes a registered nurse, clinical supervisor, and a consulting psychiatrist, and four to five case managers.

Empirical Research

Several studies have shown that intensive services such as case management are effective in decreasing days in the hospital (Ford, Young, Perez, Obermeyer, 1992; deCargas, 1996; Sherman & Ryan, 1998; Carling, 1993). A meta-analysis of nine studies examining outcomes of clients in assertive community treatment found a decline in the annual rate of inpatient days of more than 50% (Guy, 1997). Another study found reductions of 33% in the frequency of psychiatric hospitalizations and 50% in the number of inpatient days (Guy, 1997). However, Sherman and Ryan (1998) found that providing more intensive case management services than needed or providing services longer than needed is inefficient and may even impede recovery.

Castle (1997) found that treatment, which includes both medication and psychosocial rehabilitation, produces the best outcome for individuals with serious and persistent mental illness to live in the community. Many individuals continue to struggle with symptoms that may lead to rehospitalization. Gibson (1999) found that the combined approach of rehabilitation aftercare, a community support program, family support, and case management produced significant gains in the reintegration of persons with mental illness into the community. Similarly, in a study by Anthony, Brown, Rogers, and Derringer (1999) found that individuals discharged from state hospitals to a supported housing program were able to maintain living in the community during their initial year of transition into the community.

Ogilvie (1997) researched the relationships between the quality and appropriateness of housing environments and community adjustment of individuals who had been previously institutionalized because of a serious and persistent mental illness. The results of the study indicated that a client's need for community support services were significantly related to three measures of residential conditions. Those living in the worst residential settings had the greatest number of unmet service needs and a decrease in their quality of life. However, people who were living in adequate housing showed significant improvement in overall functioning.

Srebnik et al, (1995) researched individuals with a serious and persistent mental illness who were given a choice about their housing and compared this group to another group who was not given a choice. The results showed that individuals who were given choices had more residential stability and psychological well being.

Several conclusions can be drawn from the existing empirical research on individuals with serious and persistent mental illness who live in the community. First, individuals who have strong support systems such as case management, psychosocial rehabilitation, and an understanding family are more likely to be successful in community living (Ford, et al, 1992; deCargas, 1996; Sherman & Ryan, 1998; Carling, 1993; Guy, 1997; Castle, 1997; Gibson, 1999; Anthony, et al., 1999). Having a choice of adequate housing is another important factor affecting community success and quality of life (Ogilvie, 1997; Srebnik et al, 1995). Finally, having services that are available when and where needed and for the appropriate length of time is crucial to the success of individuals moving from institutions to independent living (Sherman & Ryan, 1998; Guy, 1997; Ford, et al., 1992).

Gaps in the Literature

There are several studies on the impact of different case management approaches on quantitative measures, such as days hospitalized and employment rate. However, a common gap in the literature is research on the long-term impact of deinstitutionalization on individuals. Very little qualitative research exists on this topic and even less research that uses a combination of qualitative and quantitative methods. Also, currently there is no existing research on the impact that deinstitutionalization has had on individuals receiving services from Guild Incorporated.

Conclusion

In conclusion this section addresses the research question: What has been the impact of deinstitutionalization on individuals who receive services from Guild

Incorporated. The section began with definitions of serious and persistent mental illness, deinstitutionalization, and case management. The literature review addressed a historical perspective on deinstitutionalization as well as factors that contributed to the movement. Three common theories and models found within the literature and defined in this section are Strengths Perspective, Assertive Community Treatment, and Supported Housing. The review continued with a discussion of existing empirical research on individuals with serious and persistent mental illness living in the community. The section concludes with a synthesis and integration of the research and addresses gaps found in the literature.

CHAPTER 3: THEORETICAL FRAMEWORK OF DEINSITUTIONALIZTION

Introduction

In this chapter, the theoretical framework of deinstitutionalization is discussed. The predominant theoretical perspective found in the literature is Systems Theory. Three models of case management found in the literature are the Strengths Model, Assertive Community Treatment (ACT) Model, and the Supported Housing Model. In conclusion, an application of the theoretical framework to this specific research is explored.

Systems Theory Framework

Micro Level A theoretical perspective that can be used to describe the effect that deinstitutionalization has had on individuals is Systems Theory. Payne (1997) talks about three levels of systems. The first level is micro systems. According to Andreae (1996) micro systems are systems that individuals come in contact with on a day to day basis. This level includes an individual's experience with family members, at work, or in social situations. Examples of the micro level of systems for individuals who are living in an institution may consist of roommates, peers, staff persons, and other service providers.

Meso Level The second level is the messo level. This level can be defined as the part of the environment that has an influence on the micro level (Andrae, 1996). This level includes the relationships between the larger parts of society and the smaller parts that affect the lives of the individual. For people who are living in an institution

this level may consist of clubs, work; support groups, church, recreation activities, community resources and the institution itself.

Macro Level The third level is the macro level. Most members of groups have the same macro level. This level includes the larger parts of society in which individuals live. The macro level involves culture, economics, and political structures. This level has an impact on the lives of individuals experiencing deinstitutionalization when the political zeitgeist moves from an institutional model to deinstitutionalization.

Application Individuals who moved from institutions into independent living situations experienced a systems change on all three levels, which are micro, messo, and macro. According to Johnson (1990), initial models of Deinstitutionalization failed to acknowledge these models failed to acknowledge system changes. Individuals who left institutions were left with large gaps in their systems and nothing to fill these gaps. For example, their micro level changed because they no longer lived with large numbers of peers. Most individuals were expected to move into independent living settings. Furthermore, they had also become accustomed to consistent support from the staff members in former institutions. After moving out many were left without professional support. Holley, et al., (1998) talk about how the move from hospital to community affects family members of the individuals with mental illness. These researchers found that family members expect to provide support to their family members who have a mental illness with financial and emotional support. However, family members are not able to provide as much support, as the individual believes that he or she needs.

As a result of Deinstitutionalization, individual's messo systems changed as well. In particular they left the institution. Also, many institutions provided social activities and these were stopped once people moved out (Gibson, 1999).

Finally, individual's macro level changed. They moved out because of political decisions to close the institutions that they had been living in. This occurred at the state and federal level. As a result, this move changed the culture's views of individuals living with mental illness (Guy, 1997). Many people with mental illness became homeless or lived with family members, many others moved into smaller institutions including Guild Hall. Very few were successful in independent living. Most of these individuals rotated in and out of hospitals. This became known as the revolving door syndrome (deCargas, 1996).

The Systems Theory is the best theory to describe deinstitutionalization. In addition, Systems Theory will act as groundwork for helping to define, explain, and understand ways in which deinstitutionalization has affected individuals who moved out of Guild Hall. Through this theory it will be possible to view how deinstitutionalization has impacted all three levels including Micro, Macro, and Messo.

Strengths Perspective

This model is designed to address the social desires and needs of people with serious and persistent mental illness and rests on two underlying assumptions about human behavior. The first assumption is that people who are successful in community living have the ability to use and develop their own potential. They have access to the resources they need to accomplish this goal (Sullivan, 1992). This model identifies a

person's strengths and actively creates situations (environmental and/or personal) where success can be achieved and the level of personal strength enhanced (Skinner, 1995). The second assumption is that human behavior is largely a function of the resources available to individuals, and that a pluralistic society values equal access to resources (Sullivan, 1992). People who are mentally ill may need help in securing resources in important life areas essential for human growth and development. These include employment, housing, education, social support, and medical services. A primary focus of this model is on securing environmental resources for clients. The community (people, groups, and organizations) is broadly conceived as a network of resources available to enrich the client's life (Saleebey, 1996).

Given these assumptions, case management from the Strengths Perspective is an active process focused on enriching personal strengths and client self-identity through created and existing environmental transactions. It is defined as a form of personalized helping directed at connecting individuals to resources for improving their quality of community life. Rather than focusing on intervention and treatment for an "illness", this perspective aims at providing the environmental support needed to develop and move closer toward goals identified by the individual (Sullivan, 1992).

Individuals with Serious and Persistent Mental illness have many abilities and resources. According to Dennis Saleebey (1996), individuals have strengths that can help them to solve problems as they arise. Because of these strengths individuals with serious and persistent mental illness can be viewed in light of their capacities, talents, and competencies. The strengths perspective is operationalized in these individuals by

their adaptive coping mechanisms that have allowed the majority of individuals to maintain successful community tenure after deinstitutionalization.

Assertive Community Treatment Model

The model used most often in the literature was the Assertive Community Treatment (ACT). This model includes active involvement to help individuals with serious and persistent mental illness make improvements in their level of functioning in the community. The ACT Model combines clinical and case management services, providing direct assistance and symptom management as well as facilitating a more supportive environment by direct assistance in meeting basic needs and improving social, family, and instrumental functioning (Guy, 1997).

One of the major functions of ACT is to provide the primary clinical relationship with the client and family. This involves teaching individuals about their symptoms and how to manage those symptoms so they can function well in the community. Programs following this model are characterized by interdisciplinary service teams responsible for a fixed group of clients, assertive outreach and "in vivo" treatment in the community, individualized treatment tailored for the individual, and ongoing treatment and support (Drake, 1996).

Supported Housing Model

Another common model found in the literature is Supported Housing. The main difference between the ACT model and the Supported Housing model is that Supported Housing places its emphasis on client's choices rather than client control. According to Carling (1993) the key ingredient for achieving community integration focuses on consumers' goals and preferences. Clients who are given a choice are

more successful in community living. This is an individualized and flexible rehabilitation process. There is a strong emphasis on normal housing, work, and social networks.

This approach is organized around three central principles. The first principle is that clients chose their own living situations. The second is that they live in integrated stable housing rather than mental health programs. The third principle is that clients receive the services and supports required to maximize their opportunities for success over time (Ogilivie, 1997). This principle evolved from the ACT model (Carling, 1993).

Summary

In this chapter, a theoretical framework for deinstitutionalization is presented using the Systems Theory. Three models of case management are the Strengths Model, Assertive Community Treatment (ACT) Model, and the Supported Housing Model are also discussed. In addition, an application to the current research was provided. In the following chapter the methodology of the research study is addressed.

CHAPTER 4: METHODOLOGY

Introduction

In this chapter, the research question, design, and methodology used to construct the study are presented. Further, important concepts, variables, and themes explored in the research are conceptually and operationally defined. Subsequently, characteristics of the population studied will be described along with sampling procedures used. Procedures used to verify the quality and trustworthiness of the data collected will then be discussed. Next, the interview guide will be presented along with pretest measures taken and procedures implemented for data collection. Methods used for analysis of data collected will also be explained. In conclusion, procedures to protect human subjects will be defined

Research Question

This research will answer the question of what has been the impact of deinstitutionalization on individuals who receive services from Guild Incorporated. This deinstitutionalization occurred in the 1990s and is considered to be the "second wave" of deinstitutionalization because Guild Hall was created in response to the deinstitutionalization of the large state hospitals in the 1960s. The 100 bed institution was intended to provide treatment and resources for individuals with serious and persistent mental illness in the community. In 1994 Guild Hall closed and moved most former residents into independent living situations such as an apartment.

Research Design

This qualitative study is inductive and exploratory and uses an in-depth interview of five former residents of Guild Hall who continue to receive services from

Guild Incorporated. A semi-structured interview format lasting 20-30 minutes and audio-taped for transcription purposes was used to gather data. The interview consisted of open-ended questions (Appendix C) in order to gain in-depth and detailed responses to gain a deeper understanding and meaning of personal lived experiences. The strength of this design is the ability to reveal the participant's thoughts, feelings, experiences, and perceptions thorough their direct quotations (Patton, 1997). In addition, variations of individual differences within the participants may be explored

Study Population

This research study attempts to better understand the experiences of individuals who have been impacted by deinstitutionalization. The participants in the research study will include individuals who have a serious and persistent mental illness who moved out of Guild Hall and continue to receive services from the Guild Supported Housing branch of Guild Incorporated, the former owner of Guild Hall. The study population will consist of two men and three women who met the above criteria.

Study Sample

The research study, which seeks to understand the lived experiences of individuals impacted by deinstitutionalization required participants who moved out of Guild Hall and continue to receive services from Guild Incorporated. In order to locate the participants who meet these criteria, a professional at Guild Incorporated identified prospective participants. Once prospective participants were identified, a letter of introduction (Appendix A) was distributed. The first five individuals to respond with a telephone call expressing an interest in participating in the study were

designated as participants. Therefore the participants were recruited through a non-probability and purposeful sampling

Measurement

Reliability refers to the consistency of a measurement (Weinbach & Grinnell, 1998). This qualitative research study searches for a deeper meaning of the lived experience of individuals who moved out of Guild Hall when it was deinstitutionalized. Therefore, a standard scientific criterion for establishing quality and verification of research does not apply to this specific study.

Several standards are presented by Cresswell (1998) and designed by researchers Owe and Eisenhardt (1990). Five standards were established. The first standard is that it is necessary to ensure that the research question is leading the data collection and analysis. The second standard is data collection and analysis techniques must be applied in a technical sense. The third standard is the researcher must make his or her assumptions clear. The fourth standard is the study must have overall warrant and include theoretical explanations. The final standard is the study must answer the question "so what?" and fulfil ethical questions on confidentiality, privacy, and truthfulness. The study also must use full disclosure to and with the participants (Cresswell, 1998)

Validity is when a test measures what it is supposed to. The five questions were pre-tested by the president of Guild Incorporated, Grace Tanjerd-Schmidt, the director of client services, Sue Bollinger-Brown, and two former residents of Guild Hall. All of these individuals had the same understanding of these questions and the type of information that these questions would gather.

Data Collection

An example of the data collection instrument that will is used in this research can be found in Appendix C. The first five people to respond to the letter of introduction found in Appendix A were contacted to be participants. After reviewing and signing a consent form found in Appendix B, a 20-30 minute, semi-structured interview was conducted at a date and time that was convenient for both the researcher and the participant. The interview was audio taped, with the permission of the participant, for the purposes of transcription. Furthermore, the interview was conducted at a location that assisted in the comfort of the participants. The semi-structured interview was guided by the questions found in Appendix C. The questions were pre-tested by professionals at Guild Incorporated as well as clients.

Data Analysis Procedures

Cresswell (1998) describes transcribed interviews as "the root" of qualitative research. In this study these interviews are reviewed in their entirety many times to gain a sense of the interview as a whole. Next the transcripts are separated into parts to find key concepts or categories of information that reoccur in separate interviews. Once these codes are established, a description of the experiences shared by the participants is established. Next common themes and patterns are classified for further interpretation. Finally a sense and essence of the findings is classified as well. Participants direct statements and findings in the literature support these interpretations and themes. The goal of the research is to find saturation, which is that many of the participants have common experiences when moving out of Guild Hall.

Protection of Human Subjects

Before beginning research this proposal must be approved by an Institutional Review Board (IRB) at Augsburg College. This proposal must pass through a full review because it could involve more than minimal risk to the subject. The IRB will use a risk/ benefit analysis before approving the proposal. The president of Guild Incorporated, Grace Tanjerd Schmidt has reviewed the proposal and has given permission to use subjects who are clients of Guild Incorporated and their charts. A copy of her letter granting this permission can be found in Appendix D. Prior to participating in the research potential subjects will be asked to sign a consent form which outlines the possible risks and benefits associated with participating in this research study. A copy of the consent form can be found in Appendix B.

Participants were informed in the beginning of the interview that if they felt overwhelming discomfort at any time during the interview process, they were encouraged to stop participating in the study without consequence. Every participant was given referral information to counselors regardless of whether they reported any emotional or psychological discomfort. Records of this study were kept confidential. Audio taped interviews and transcriptions were kept in a locked drawer and were destroyed no later than August 31, 2001. The researcher and thesis advisor were the only people who had access to the material. Any identifying information from the interview was altered or removed to ensure privacy. All information was kept confidential. No names or identifiable information about participants were be used in the study.

Summary

This chapter discussed the design method, which was used in the research study of the experiences of individuals who were impacted by the deinstitutionalization of Guild Hall. Key concepts and themes were likewise defined. Subsequently, charastics of the study population were identified along with the procedure used to recruit participants. Procedures were next addressed, including measurement issues, data collection procedures and data analysis measures used. Finally, measurements used to ensure the protection of human subjects were addressed. In the next chapter, results of the study will be presented.

CHAPTER 5: Findings

Introduction

In this chapter, results of the study are presented. To begin, demographic characteristics of the participants are described. Next, participants' responses to five questions asked to elicit participants' personal experience with deinstitutionalization. Consecutively, the experiences of the individual participants are presented in response to the first research question: what is the impact of deinstitutionalization on individuals who moved out of Guild Hall and continue to receive services from Guild Incorporated? Common experiences by participants are addressed within each question.

Profile of Participants

The participants in this study include five individuals who have been diagnosed with a serious and persistent mental illness. These individuals moved out of Guild Hall when it closed and continue to receive case management services from Guild Incorporated. Study participants include three females and two males. Each of the study participants was living independently in the community at the time of the study.

Leaving Guild Hall

Fear and Helplessness

In searching for the experience of individuals facing deinstitutionalization, participants were first asked what it was like to leave Guild Hall. The most common answer in response to this question, was a description of feelings of fear about moving. Many also talked about feeling helpless that this decision was made for them

and without their input. For example, a participant stated "When I found out that Guild Hall was closing and I had to move out and I felt very vulnerable and exposed and at high risk at that time." Another participant said "I kinda felt like a little guy being moved around like a pawn on a chess board." Another participant said "I didn't really want to move but staff were telling me 'everyone is moving' and I had no choice."

Loss of Support

Participants described a feeling of loss. Several participants talked about the support, friendships, and structure that living in the institution had provided. One participant commented "At the time it was very hard to leave. I had a lot of friends there and I was kinda used to being there I think." Describing feeling lonely one participant said, "The first thing of significance that I experienced when moving out of Guild Hall was the loneliness. This person went on to say that he wished he had some way to stay in contact with other former residents. "We didn't have a mechanism to keep in touch with each other. So the people I stayed in relationship with turned out to be the ones I happened to run into." Likewise, another participant said, "when I lived at Guild Hall, my need for socialization was pretty much addressed without me even going out the door. That all changed when I had to get my own place. One participant even talked about asking another resident to stay at his apartment. "She stayed 15 months with me that pretty much did away with the loneliness. So I got benefit out of that."

Financial Burden

Furthermore, many participants described the financial burden of maintaining independent living. "There was a slump financially because I had Guild finances (through the Supported Housing Program) to buy a table and chairs, sofa and a bed. Most of my start-up things." This participant went on to say "but there are all kinds of things you only buy rarely like salt and pepper and even non-food items like toilet paper. I didn't budget very well and I quickly ran out of money." Another study participant talked about how people living at Guild Hall were only given a monthly stipend of $70 a month for personal needs and the rest of their money form Social Security went to pay for Guild Hall. This person said it was difficult to learn to budget and entire check including money for rent, utilities, food, and other necessary items.

Help with the Transition

Community Supports

In connection with participant's descriptions of their experiences of leaving Guild Hall, study participants were next asked to recall and describe what helped them with the transition of moving from an institution to independent living. The most frequently cited response was services they received while living in the community. "I guess the main thing at that time was that I was given extra supports. I started seeing a psychologist, and a county nurse would come to see me" was one participants comment. Another said " I guess those extra supports kicked in at that time." A different participant commented said that it helped to have Guild staff (from the

Supported Housing program) visit weekly and assist with tasks such as grocery shopping and transportation.

Finding Structure

One participant described the process of finding structure after leaving the institution.

> *Right after moving out I assembled what was going to be my structure. I came up with four rules we had at Guild Hall. You had to wash your own clothes. You had to clean your room. You had to make your own meals. And you had to take your meds. Those were all the rules we had to follow at Guild Hall. When I figured that out for myself then I said 'I know the key to success'. I know that as long as I could stick within those four rules I could make it on my own. After I got that figured out, I was asked to speak to the people at Family Style (a similar institution to Guild Hall deinstitutionalizing around the same time). That's what I told them. You have to structure your life a little if your gonna survive on your own. You can't get by without some rules*

This participant talked about finding basic structure with four rules that helped with successful independent living. This participant was even invited to share experiences and offer assistance to other individuals facing deinstitutionalization.

Planned Social Activities

Most of the participants talked about the importance of planning social activities. With limited financial resoruces and transportation difficulties participants talked about how easy it was to isolate in their apartments. Many participants mentioned the annual Guild Christmas Party, which serves in part as a reunion of

former Guild Hall residents. One participant also mentioned how the fall trip to the apple orchard is an important time to be with a group of other people and have fun.

Satisfaction with Current Living Situation

In searching for a deeper understanding of the experience of deinstitutionalization, participants were asked if they were satisfied with their current living situation. All five participants talked about preferring independent living to institutionalization. However, most mentioned the limitations that having a mental illness has on the choices they have over where they can live and the things they can afford. One participant talked about how he would felt bitterly jealous of everyone, who lived in a house, had a car, and families. He described this jealousy as "acid on the brain". Finally this participant talked about realizing that happiness meant accepting his current situation. He said, "To get happy, you have to have a lot of acceptance. Sometimes you have to reign yourself in and not dream the big dreams that will not ever be attainable unless you win the lottery".

Moving back to Guild Hall

Study participants were asked the hypothetical question if Guild Hall still existed would he or she ever chose to move back. All five participants indicated that they would move back if they had to but every participant in this study preferred living independently. One participant said "if I had to give up my independent living and go somewhere. That's probably the first criteria I'd look for. Someplace like Guild Hall" Another participant said, "I really liked it when I was there because I had friends. But it's kinda nice to have my own place and make my own food. I like that better".

Summary

This chapter presented findings from the data analysis. In summary, participants described their personal experiences with deinstitutionalization. Three common themes emerged from the first question about the individual's experiences with leaving Guild Hall. The common themes were fear and helplessness, loss of support, and financial burden. In response to the second question participants sited community supports and finding structure as things that assisted with the transition of deinstitutionalization. The third question asked if participants were happy with their current living situation and all of the participants indicated that they were in fact pleased with their living situations. The final question was hypothetical and asked if participants would move back to Guild Hall and every participant answered that they would if necessary but they preferred living independently.

Chapter six will present a discussion on the findings of the study in relation to current literature involving deinstitutionalization and it's impact. Chapter six, which is the final chapter, will also describe strengths and limitations of the study. In conclusion, implications for practice and policy, as well as implications for further research will be offered.

CHAPTER 6: DISCUSSION

Introduction

The final chapter will present a discussion of the major findings of the research study and connect prominent points to the literature. Strengths and limitations of the study will likewise be presented. And finally, implications for social work practice and policy, along with implications for further research will be discussed.

Major Findings

The purpose of this study was to find the lived experience of individuals who moved out of Guild Hall when it deinstitutionalized. Specifically the study asked: what has been the impact of deinstitutionalization on individuals who receive services from Guild Incorporated? To answer this question, participants were asked to answer four questions. The first question asked what it was like to leave Guild Hall. The second question asked what helped with the transition of leaving Guild Hall. The third question asked if participants were happy with their current living situation. Finally, the fourth question asked if they could would they move back to Guild Hall.

Leaving Guild Hall

In describing their experiences of leaving Guild Hall, participants talked about three major themes. The first theme was fear and helplessness. Participants said that their initial reaction to finding out that Guild Hall was deinsititutionalizing was feeling that they had no input and the decision was already made. Participants talked about feeling helpless against this major change affecting their lives. Participants also described loss of support and financial burdens while moving from an institution to independent living. These findings are consistent with Holley, Hodges, and Jeffers

(1998) research, which states that individuals leaving institutions often grieve the loss of the stability that institutional living provides.

Help With the Transition

All of the study participants talked about the importance of community support in assisting with the transition from institutionalization to independent living. These community supports included case management services, home visits from a nurse, supported housing staff, and bus passes. Carling (1993) talks about the importance of providing community support including housing assistance, help with medications, and peer support when working with individuals with mental illness. Additionally, Holley, Hodges, and Jeffers (1998) found that individuals with a mental illness express clear preferences about key aspects of community based care.

Finding Structure was the second most frequent response to what helped individuals with the transition of moving out of Guild Hall. One individual talked about formally setting up four rules for independent living including washing clothes, keeping the apartment clean, making meals, and taking medications. Interesting very little research was found on the importance for individuals with serious and persistent mental illness to create personal structure in successful independent living.

Satisfaction with Current Living Situation

Current literature on deinstitutionalization suggests that most individuals with a serious and persistent mental illness prefer independent living of their own choosing that they do not have to share with others (Holley, Hodges, & Jeffers, 1998). This existing research was also true for the individuals in this study. All five participants indicated that they preferred independent living even though it means making

sacrifices. This was further validated when participants indicated that they preferred independent living, but as a second choice they would consider moving back to someplace like Guild Hall.

Conclusion

Strengths and Limitations

A primary strength of the study is the in-depth experiences participants shared. The qualitative design, which included open-ended questions, allowed participants to recall and describe their experiences with the deinsitutionalizaion of Guild Hall. The variety of individuals interviewed including 2 men and 3 women further allowed a wide range of experiences to be shared. In addition, a deeper insight as to how the experiences have impacted their lives was detailed. Finally, in-depth interviews strengthen the study by allowing the ability to reveal participant's thoughts, feelings, experiences, and perceptions.

There are however, several limitations to the study. The first limitation involves the participants all being deinstitutionalized from Guild Hall, which poses a limitation due to the possibility that other institutions may have had different procedure of deinstitutionalizing and this research would have limited application for those institutions. Likewise, individuals moving out of different institutions may have had different experiences. By limiting the study to individuals who moved out of Guild Hall, the study lacks the experience and perception of individuals who have moved out of other institutions. Also every participant in this study has maintained independent living and was doing well at the time of the interview. In essence, only

the participants who have had successful experiences with deinstitutionalization are studied in this research.

Implications for Social Work Practice and Policy

Deinstitutionalization is a current trend in mental health. The first wave occurred when the large state hospitals closed and the second wave occurred when smaller community-based institutions closed. This research focuses on the deinstitutionalization of Guild Hall, which occurred in 1996. Ninety one individuals moved out of Guild Hall and as of June 30, 2000 fifty two individuals continued to receive services from Guild Incorporated. From the remaining fifty two individuals forty individuals continue to maintain independent living in the community. Therefore this could be considered a successful deinstitutionalization. Findings from this study include five individuals who moved out of Guild Hall when it closed and their personal experiences with deinstitutionalization. These findings can increase the awareness of the experience moving from an institution to independent living in the community. Further, in response to successful deinstitutionalization, possible policy changes or programs that respond to the needs of deinstitionalized individuals may be such as increased funding during the transition and lower client to case manager ratios.

All participants in this study expressed feelings of fear and helplessness during the deinstitutionalization process. The individuals leaving Guild Hall felt they were losing the support of the structured living environment. The literature surrounding the impact of deinstitutionalization on individuals moving out to independent living suggests providing individuals with formal support such as case management, nurses

to visit at home, and representative payees, who help individuals pay bills such as rent. One study participant talked about he importance of receiving an unlimited bus pass. Something as simple as a bus pass may make a big difference for individuals who are more isolated in their new apartments compared to when they lived at Guild Hall.

Many participants also discussed the importance of informal supports particularly with peers. Examples of informal support suggested by study participants include voluntarily exchanging telephone numbers, reunions of former residents, and other social gatherings. One study participant talked about the importance of the annual Christmas party because other former residents at Guild Hall also attended the party.

In addition to facilitating formal and peer support it also might be important to create an atmosphere conductive to recognition and acknowledgement of emotional reactions from individuals going through deinstitutionalization so their feelings can be coped with rather than suppressed or denied. Even acknowledging that moving from an institution to an independent living situation can potentially be a frightening experience. All of the study participants said they felt scared when they heard that Guild Hall was closing.

Educational opportunities may also aid in the ability of individuals transitioning from institutional life to independent living. Existing literature on deinstitutionalization suggests that providing education may help alleviate concerns about the process (Ford, Young, Perez, et al., 1992). Individuals could be taught independent living skills such as cooking and budgeting. One study participant talked about presenting his "rules" for successful independent living to another group of

individuals facing deinstitutionalization around the same time as the closing of Guild Hall. This appeared to be a good example of peer education on what to expect and how to cope with independent living.

Implications for Further Research

Some participants in this study reported a personal growth due to the experience of critical incidents. For this reason, these participants may have been more willing to participate. Therefore, research could be done involving participants who did not have positive experiences with deinstitutionalization in order to understand their unique experiences. Through this, an understanding may be gained of the impact of deinstitutionalization. Likewise, a study involving a larger number of participants may allow for greater and more diverse experiences and a deeper understanding of the experiences of deinstitutionalization.

Further research may also include participants who deinstitutionalized from various institutions in order to determine differing experiences based on diverse experiences in the procedure. Participants reported personal growth due to deinstitutionalization and specific ways in which they coped with the experience. Further research may be conducted in order to compare a variety of sources to aid in the transition from institutionalization to independent living.

Summary

There has been much research conducted on the "first wave" of deinstitutionalization where the large state hospitals closed. However, there is very little research on the "second wave" of deinstitutionalization which occurred in Minnesota in the mid 1990s. This deinstitutionalization closed several of the smaller

institutions. Most of these individuals moved out independent living with community resources in place. This research explores the individual's experiences who moved out of Guild Hall in 1996. Findings of this study can help direct future deinstitutionalization as another smaller group home in Ramsey County will soon decrease beds and residents will have shorter stays. Furthermore, findings in this study can assist social workers that are working with individuals in the community to successfully maintain independent living.

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Appendix A

Letter of Introduction

Hi, my name is Meredith Foster. I am a case manager at Guild Supported Housing Service. I am also attending classes at Augsburg College where I am earning a Masters Degree. I am also conducting a research study for a final thesis requirement. For my thesis, I have chosen to study what the impact of deinstitutionalization on individuals who receive services from Guild Incorporated. The Institutional Review Board at Augsburg College has approved this study.

There is research and literature on deinstitutionalization of large state hospitals. However, very little research exists on the deinstitutionalization of smaller residences. This study would provide a longitudinal view of the deinstitutionalization of Guild Hall. The purpose of this study is to hear about personal experiences of the individuals who moved out of Guild Hall and continue to receive services from Guild Incorporated.

Participant's confidentiality will be protected. No names or identifiable information about participants will be used in this study.

Indirect benefits of the study may include improving the understanding of social work practitioners, as well as the researcher, regarding the impact of deinstitutionalization. Participants may also find it beneficial to have an opportunity to reflect and share personal experiences.

The study also has a minimal risk if you choose to participate. During the interview you will be asked to recall particularly difficult experiences that may have been highly emotional for you. Recalling the experience may elicit normal, but strong, emotional reactions. Should this occur, you may choose to withdraw from the study at any time with no consequences. Additionally, if overwhelming discomfort occurs due to the interview questions, a phone number will be provided for crisis intervention.

Participation is voluntary and confidential. The process would involve a 20-30 minute, in-person interview in which I would ask you a few questions. With permission I would like to audio tape the interview for transcription purposes. All audio tapes and transcripts will be destroyed for confidentiality purposes no later than August 31, 2001. Only the researcher and thesis advisor will have access to tapes and transcripts.

If this is something that you would be interested in participating in please contact me at (651) 291-0067 in order to determine a time that is convenient for an interview. If this does not interest you, thank you for your time.

Or if you need further information, you may contact my thesis advisor: Phu Phan, Business Phone: (612) 330-1375

Thank you,

Meredith Foster

Appendix B
Consent Form

From Institutionalization to Independent Living: A Study of the Impact of Deinstitutionalization on Individuals Who Receive Services From Guild Incorporated.

Consent Form

You are invited to participate in a research study designed to look at the impact of deinstitutionalization on individuals who receive services from Guild Incorporated.. Participation is completely voluntary. The researcher is a case manager at Guild Supported Housing Services and is conducting the study as part of a thesis requirement for the Masters in Social Work Program at Augsburg College. You have been identified as a possible candidate for participation because you moved out of Guild Hall when it closed and you continue to receive services from Guild Incorporated. Please read this consent form and ask any questions prior to agreeing to participate in the study.

Study Purpose

The purpose of the study is to hear about personal experiences of people who moved out of Guild Hall themselves in order to gain and give readers a deeper understanding of the impact that deinstitutionalization has had in your life.

Study Procedure

The study consists of one 20-30 minute interview, which will be audio taped with your permission. You will be asked to relate experiences you have had with critical incidents experienced while working as a hospital social worker. Once the interview has been interpreted, you may be asked to review and verify the interpretation to reflect your experience.

Risks and Benefits

Indirect benefits of the study may include improving the understanding of social work practitioners, as well as the researcher, regarding lived experiences with stress and coping with critical incidents. Participants may also find it beneficial to have an opportunity to reflect and share personal experiences. The study also has a minimal risk if you choose to participate. During the interview you will be asked to recall particularly experiences that could be emotional for you. Recalling the experience may elicit normal, but strong, emotional reactions. Should this occur, you may choose to withdraw from the study at any time with no consequences. Additionally, if overwhelming discomfort occurs due to the interview questions, participants will be provided with the phone number for Minneapolis Crisis Intervention at 612-347-3161.

Confidentiality

Records of this study will be kept confidential. Audio taped interviews and transcriptions will be kept in a locked drawer and will be destroyed no later than August 31, 2001. The researcher and thesis advisor will be the only people to have access to the material. Any identifying information from the interview will be altered or removed to ensure privacy. Because of the small sample size, I cannot guarantee that someone may not recognize your story. No names or identifiable information about participants will be used in the study.

Voluntary Participation

Your decision to participate is completely voluntary. If at any time you decide to not participate, you may withdraw with no consequences.

Questions/Contacts

The researcher conducting the study is Meredith Foster. If you have any questions please contact the researcher at (651) 232-4398. Questions and concerns may also be directed to Phu Phan, Thesis advisor, Augsburg College, (612) 330-1375.

Consent Statement

Before you sign this form please be sure to have any questions regarding this study answered. I will attempt to answer any question that arises, prior, during or following the study.

AUTHORIZATION: I,_____, have read this consent form and decide to participate in the research project described above. My signature indicates that I give permission for information I provide in the interview to be used for a thesis research project.

Signature_____

Date_____

Telephone Number _____

In addition:

I give permission to be audio taped.

Signature _____ Date_____

I give permission to the use of direct quotes from my interview.

Signature _____

Date_____

Appendix C

Interview Questions
To be asked by the researcher

Research study question: What was the impact of deinstitutionalization on individuals who receive services from Guild Incorporated?

1) What was it like to be a resident at Guild Hall?
2) Tell me what it was like for you to leave Guild Hall?
3) What helped you with the transition of leaving Guild Hall?
4) Are you happy with your current living situation?
5) If you could, would you move back to Guild Hall?

Prompts:

1) Tell me more about that.
2) Can you clarify that?
3) What was it like for you to have had this experience?
4) For instance?