EXPERIENCES OF ADULT MENTAL HEALTH CARE SERVICE USERS AND THEIR FAMILIES UPON DISCHARGE OF MENTAL HEALTH CARE SERVICE USERS, TO THEIR FAMILIES IN THE DURBAN AREA, FROM EKUHLENGENI CARE CENTRE DURING MAY 1999 TO DECEMBER 2001.

AMRAVATHY REDDHI

Submitted in fulfilment of the requirements for the Degree of Masters in Social Science in the Faculty of Community and Development Disciplines, University of KwaZulu-Natal.

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DECLARATION

Submitted in fulfilment of the requirements for the degree of Masters of Social Science, in the Graduate Programme in the Faculty of Humanities, Development and Social Science, University of KwaZulu-Natal, Durban, South Africa.

I declare that this dissertation is my own unaided work. All citations, references and borrowed ideas have been duly acknowledged. It is being submitted for the degree of Masters in Social Science in the Faculty of Humanities, Development and Social Science, University of KwaZulu-Natal, Durban, South Africa. None of the present work has been submitted previously for any degree or examination in any other university

Amravathy Reddhi
Student Name

14 October 2008
Date

ABSTRACT

This qualitative study explores the experiences of adult mental health service users as well as their families upon discharge of service users, to their families in the Durban area, from Ekuhlengeni Care Centre (ECC) during May 1999 to December 2001. In so doing, the aim was to ascertain the nature of mental health service users' adjustment to living in the community, their impact on the home environment, to identify gaps in community care and to provide suggestions on resolving these gaps.

The study was guided by a qualitative research paradigm and utilized an exploratory descriptive research design. Availability sampling was used. Unstructured face-to-face, in-depth interviews were conducted with four mental health service users (MHSUs) and six family members.

The results of the study reveal the many dilemmas that both MHSUs and their relatives experience because of the lack of support and services available in the community. There is overwhelming evidence to suggest that the environment is ill suited at all levels to meeting the needs of MHSUs and their relatives. This study examines the challenges experienced by MHSUs and their relatives and makes recommendations for practice and policy that can contribute to improved service delivery.

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LIST OF ABREVIATIONS

ABH	Aryan Benevolent Home
AIDS	Acquired Immune Deficiency Syndrome
CBOs	Community based organisations
CHC	Community health centre
ECC	Ekuhlengeni Care centre
EMRS	Emergency Medical Rescue Services
FBOs	Faith based organisations
HIV	Human immunodeficiency virus
KZN	Kwa – Zulu Natal
MDR	Multi-drug resistant
MHCA	Mental Health Care Act
MHCPs	Mental health care practitioners
MHSU	Mental health service user
MHSUs	Mental health service users
MPs	Ministers of Parliament
NETRHA	North East Thames Regional Health Authority
NGOs	Non-governmental organisations
NHS	National Health Service
PHC	Primary Health Care
SA	South Africa
SAPS	South African Police Services
TAPS	Team for the assessment of psychiatric services
TB	Tuberculosis
UK	United Kingdom
USA	United States of America
XDR-	Extreme-drug resistant

CHAPTER ONE
INTRODUCTION TO THE STUDY

INTRODUCTION

This study seeks to gain an understanding of the experiences of mental health service users and that of their families after the mental health service users' discharge from a chronic institution. This was done through a qualitative approach and by conducting in depth, one on one interviews with mental health service users and their caregivers. The overriding objective of this research was to ascertain the nature of mental health service users' adjustment to living in the community, be it positive or negative, their influence on their family members as well as to ascertain any gaps that exist in community care and how these gaps can be resolved.

This chapter provides an overview of the background to the study, the problem statement, the main aim of the study, research objectives and questions, underlying assumptions, anticipated value of the research and concludes by describing the theoretical framework that underpinned the study.

BACKGROUND TO THE STUDY

The researcher was a Senior Social Worker at Ekuhlengeni Care Centre, a chronic mental health care facility that was established in 1975. It used to provide custodial care to Zulu speaking mentally ill persons. However, since 1995 the facility started providing services to all race groups. There was also a move from the provision of custodial care to a multi-disciplinary approach to patient care. The centre provides care for 1100 chronic mentally ill persons. It is located approximately 25 km south of the Durban city centre. Mental health service users (MHSUs) are placed at Ekuhlengeni when they are found to be unmanageable in

the community. Generally, these service users would have had numerous admissions to acute hospitals.

In keeping with current mental health care policy, which aims to provide community care, attempts are made on a continuous basis to return mental health service users (MHSUs) to the care of their families, when they have been found suitable for discharge by the multi-disciplinary team. Alternatively, MHSUs are also placed in community based residential facilities such as old age homes, and halfway houses. To date there have been no investigations conducted to ascertain how these MHSUs are coping and adjusting in their new environments. This research study will therefore provide valuable information about the MHSUs success in adapting to their new environments. The study will focus only on those MHSUs who have been placed with their families.

Community based care is an established concept in countries such as England, Scotland, Ireland and the USA. In fact, it started in Scotland in the 19th Century where an approach called *"boarding out"* was used according to Sturdy and Parry-Jones (1999:p86). They indicated that families fostered patients from institutions. These families were usually not related to the patients and were paid a fee to take care of these patients. Since then many other countries have followed their example by aligning their mental health policies to the promotion of the care of the mentally ill in the community.

Historically the care of the mentally ill in South Africa has reflected a strong reliance on long-term custodial care in institutions. However, the South African government is following world trends to reduce the beds allocated to long-term institutional care. This is reflected in the KwaZulu- Natal Department of Health "Strategic and Implementation Plan for delivery of Mental Health Services in KwaZulu-Natal" launched in 2003.

This plan is guided by the principle that the management and treatment of mental disorders at primary health care level is essential in ensuring that most people have access to services, and that community care is more beneficial than institutional care on the quality of life of individuals with chronic mental disorders. This plan for the delivery of mental health services in KwaZulu-Natal is in line with the National Mental Health Act No 17 of 2002 and it aims to provide comprehensive mental health care for everyone in the province. However, there remains an ongoing debate as to whether institutional care or community care is the best for chronic mentally ill persons.

Studies have also produced contradictory results as to the effectiveness of these two types of care. There is an overwhelming feeling that the institutionalisation of people with mental disorders promotes their segregation and isolation from the rest of society. This resulted in the institution replacing the family and community as the primary caregiver. There is also the belief that community care is more effective than institutional care on the outcome and quality of life of individuals with chronic mental disorders. The notion is that care and treatment in the community results in greater chances of the mentally ill being rehabilitated. Mansell and Ericsson (1996: p247-248) commenting on studies carried out in Britain, Scandinavia and the USA on the de-institutionalisation and community living of intellectually disabled people stated, " *empirical evidence available suggests that the opportunities provided by better conditions have been translated into a better quality of life... people have more normal patterns and rhythms of life; they grow and develop as individuals; they use services and facilities available to the wider public; and they and their relatives express satisfaction"*. In other words, the placement of these service users in community settings, lead to an improved quality of life by establishing social relationships with individuals outside their family circle or being meaningfully employed. This has also lead to community mental health services integrating the care of a community's mental health needs with the rest of their health needs.

However, during the researcher's employment at Ekuhlengeni Care Centre as a Social Worker, one of the challenges faced on a continuous basis was the severe shortage of residential facilities in the community. This had a negative impact on mental health service users who had been assessed to be 'ready for discharge' but who had no family to go to for one of three reasons. Firstly, they had lost contact with their relatives. Secondly their relatives home conditions did not provide a conducive environment for their discharge (this was ascertained in instances where investigations of home circumstances were conducted), and thirdly, where family refused to accept the mental health service users on discharge. This clearly indicates a lack of reunification services with families and points to an overall lack of planning in mental health services.

There is also a concern as to whether the discharge of these MHSUs has been merely a shift in responsibility from Ekuhlengeni Care Centre to the family. The researcher strongly believed that this study needed to be carried out in view of government's policy to provide community based care, and the pressure on staff at Ekuhlengeni Care Centre to relocate inpatients, back to the community.

It was also hoped that this research would help shed some light on the state of aftercare services provided in the community and whether government should have focused initially on strengthening the resources and support structures in the community before embarking on a programme of de-institutionalisation.

Literature reviewed has also indicated that there are contradictory reports on the perceptions of service users concerning the quality of their lives and their experiences in the community. However, the researcher aims to provide further clarity by exploring the experiences of service users who have been discharged from a long-term facility into the community.

PROBLEM STATEMENT

From my experience in the mental health field, as well as my interaction with other professionals, there has been a concern that aftercare services provided in the community is not adequate and the necessary community structures are not in place to ensure that caregivers are provided with the necessary support to assist them in coping and managing their mentally ill relative. However, there has been no empirical study to establish whether these are the challenges faced by service users and their families upon the users' discharge from Ekuhlengeni Care Centre.

MAIN AIM OF THE RESEARCH

The main aim of the research was to investigate the experiences of adult Mental Health Care Services Users as well as their families upon discharge of service users, to their families in the Durban area, from Ekuhlengeni Care Centre during May 1999 to December 2001.

RESEARCH OBJECTIVES

The research objectives were to:
1) To explore the positive aspects of Mental Health Service User's adaptation to living in the community.
2) To explore the challenges faced by service users in their adjustment to life in the community.
3) To determine what after-care services were offered in the community.
4) To explore the experiences of the families of service users when MHSUs are returned to their care.
5) To obtain recommendations from the service users and their families on areas that should be focused on when conducting pre-discharge programmes at E.C.C.

RESEARCH QUESTIONS

1) What were the positive aspects of MHSUs adaptation to living in the community?

2) What were the challenges faced by service users in their adjustment to life in the community?

3) What after-care services were offered in the community?

4) What were the experiences of the families of service users when MHSUs are returned to their care.

5) What are the recommendations from the service users and their families on areas that should be focused on when conducting pre-discharge programmes at E.C.C.?

UNDERLYING ASSUMPTIONS

The study was guided by the two assumptions:

1) Aftercare services provided in the community are insufficient to maintain the stable functioning of MHSUs.

2) The policy of community based care is implemented without ensuring that adequate resources and support exists in the community.

ANTICIPATED VALUE OF THE STUDY

This study has a number of potential benefits. Firstly, it will add to the body of knowledge regarding the experiences of MHSUs who have been discharged from a long-term chronic institution, back into the community. What is important is that this will be within a South African Context. Most of the literature, which is currently available, is based on findings in England, USA and other European countries. The research will focus on the experiences of both the MHSUs and their families. It is hoped that the study will provide essential information that can

be utilized by mental health professionals in the planning of effective community services.

Secondly, ascertaining the experiences of MHSUs will undoubtedly provide important information that can be utilized for planning pre-discharge programmes at Ekuhlengeni Care Centre and other similar institutions. This will then lead to improved service delivery. MHSUs are prepared for discharge to the community, based on areas of function that mental health care practitioners (MHCP) consider necessary for MHSUs to live in the community. This study may therefore provide valuable contributions from MHSUs and their families, based on their experiences as to what areas of rehabilitation they consider pertinent to the MHSU's successful adaptation to living in the community. This can be useful to the multi-disciplinary team in evaluating the pre-discharge programmes and, if necessary adapting it to be more relevant to the skills required by MHSUs when discharged into the community.

Thirdly, the study may also provide pertinent information concerning support structures or the lack thereof at community level. This information can be used to lobby for improved services for MHSUs in the community and to encourage the KZN Directorate of Mental Health to address the deficiencies in service provision at the community level.

Fourthly, the research conducted will also provide an opportunity for information to be obtained from relatives. Mansell and Ericsson (1996) indicated that one should be able to gain an understanding of how relatives view the change from institutional to community services because relatives play a significant role in MHSUs integration into the community. Tuvesson and Ericsson (1996), in their study found that relatives raised concerns that indicated that there were problems in the structure of support in the community. This study will therefore attempt to provide information about the experiences of MHSUs' families, be it negative or positive.

THEORETICAL FRAMEWORK

The study was guided by the ecosystems perspective because it is concerned with the person in the environment (i.e. social, political and economic context). According to Greif and Lynch (1983: p11) this perspective *"focuses the social worker's vision upon the way that people and environmental forces interact".*

The principles of interdependence, balance, adaptation and wholeness are also very important in the ecological perspective. This approach sees people as constantly adapting. They change and are changed by the environment. In order to function well in society, people must maintain a good fit with their environment. According to Bronfrenbenner (1979, 1989, 1993 in Berk, 2000), the ecosystems perspective sees people as part of a complex system of relationships involving levels of environment. The different levels of environment have a major impact on individuals.

These levels are:

Micro level: This level refers to the first level of the environment, which encompasses all the activities and relationship of individuals in their immediate setting. The family is a very important part of the microsystem. The way that the family relates to the MHSU is very important. The family has to have an understanding of the MHSU's illness. In the ecosystems perspective, people are seen as both influencing their environment as well as been influenced by the environment (Berk, 2000). For example, if the service user refuses to do any chores at home it could be understood that amotivation is a negative sign of mental illness. The family must then agree on some form of behaviour modification in order to help the MHSU overcome being amotivated. However, if the MHSU is constantly nagged, it may result in him acting out, which the family may view as a relapse or a behaviour problem. The manner in which the family relates to the MHSU, affects the behaviour of the MHSU. Therefore, it is necessary that the family understand mental illness. The local community also

forms part of the microsystem. Mental health service users, like others, require information, resources and other support services to maintain and develop themselves. According to Healy, (2005) from an ecosystems perspective, a supportive community must be promoted. This will ensure that mental health service users have some independence from family and the health and welfare systems that have such dominance in their lives. MHSUs must be linked to support groups in their communities. If this network is absent then it must be created. Inadequate support in the community may result in MHSUs relapsing or presenting with problematic behaviour. This will impact negatively on the family and community resulting in problems in their fit with the environment. Due to their inability to maintain and develop themselves in the community, this will eventually lead to institutionalisation.

At an institutional level, MHSUs could be supported by identifying and facilitating their access to the job market. If we are unable to do this, we may need to advocate at local institutional and broader policy levels for increased access to the job market for MHSUs.

Mesosystem: The mesosystem is the second level of Bronfrenbrener's model. It relates to relationships between microsystems that contribute to development. Here the Departments of Health and Social Services need to provide services to ensure the continued stable functioning of the MHSUs in the community. Health services need to ensure that mechanisms are in place to monitor how MHSUs are coping with living in the community. For example, compliance to medication must be monitored and should any problems arise they should be dealt with immediately in order to avoid a relapse in MHSUs condition. The Department of Health needs to liaise with the Department of Social Services to ensure that MHSUs have access to social assistance grants. MHSUs must also be linked with the relevant social welfare agencies that will offer necessary services to them.

Exosystem: This level refers to social structures that do not have MHSUs but has an impact on their experiences in the immediate surroundings (Berk, 2000). Concerning MHSUs, this system is extremely important. The support that the families of MHSUs receive from their extended families, neighbours, friends and other community members also contribute to MHSUs stay at home being successful or not. The researcher has heard many reasons from relatives (during the course of her employment at the facility) as to why they are unable to keep the MHSUs at home. Reasons provided were: accommodation at home is insufficient; everyone at home was working and as a result there is no one at home to supervise the MHSU; the community will not accept the service user due to behavior presented prior to admission and another reason is that of lack of finances. If social networks are supportive of the families, it will be easier for these families to cope with the MHSUs being at home.

Macrosystem: The macrosystem refers to the outermost level. This level relates to the values, laws, customs, and resources of cultures that affects the experiences and relationships of individuals in the more inner levels of the environment (Berk, 2000). At a macro level, it is imperative that awareness campaigns are promoted and conducted on a large scale in order to alleviate the stigmas attached to mental illness. People must be educated about the rights of the MHSUs. People also understand mental illness from their cultural perspectives, for example, it does happen that service users are taken to traditional healers for treatment. However, if they are educated about mental illness, they will realize it is similar to other medical conditions that require specific treatment in order to be controlled. The move to overcome stigmatisation is evident in government's policy to integrate psychiatry into primary health care.

Government has given priority to the mentally ill persons by implementing the new mental heath act which emphasizes the need for MHSUs to be taken care of, in the community.
This framework will guide the data collection and data analysis.

RESEARCH METHODOLOGY

An exploratory-descriptive research design was used. The researcher interviewed six family members and four Mental health service users by means of in-depth interviews. The interviews were conducted to explore the experiences of mental health service users (MHSU) who had been discharged from Ekuhlengeni Care Centre as well as experiences of their families. The study was guided by a qualitative research. Availability sampling was used and data was collected by means of unstructured face-to-face interviews.

PRESENTATION OF DISSERTATION

In this chapter, I introduced the background to the study, the problem statement, the main aim of the study, research objectives and questions, underlying assumptions, anticipated value of the research as well as the theoretical framework that underpinned the study.

Chapter two provides an overview of the history of care for people with mental disabilities. It looks at services provided to the mentally ill, before and during the days of the asylum. It explores mental health services and policies in South Africa, taking into account the establishment of asylums in South Africa, mental health policies during apartheid, as well as the transformation of mental health legislation in a democratic South Africa.

Chapter three pays particular attention to understanding de-institutionalisation and community care. It looks at an appropriate definition of de-institutionalisation and then goes on to explore the process of de-institutionalisation, focusing on the factors necessary for successful de-institutionalisation. The discussion hereafter is on community care, which touches on the advantages as well as the challenges of community care. The chapter ends with the South African experience of de-institutionalisation.

Chapter four details how the research was conducted within an eco-systems perspective. The research paradigm, the research design, the sampling strategy, data collection methods and analysis are explained and described. It focuses on ethical issues in terms of trustworthiness and authenticity and concludes with a description of the limitations of the study.

Chapter five introduces the participants. The experiences of the participants are heard and the results are analyzed. The problems experienced by the participants are interpreted in light of the current service delivery aimed at MHSUs and their families.

Chapter six concludes the thesis. It summarizes the main findings in the study and makes suggestions for improvement in service delivery as well as recommendations for policies.

CHAPTER TWO

AN HISTORICAL OVERVIEW OF THE CARE OF THE MENTALLY ILL: LITERATURE REVIEW

INTRODUCTION

This study is located within the historical developments regarding care for people with mental disabilities. This chapter provides an overview of the history of care for people with mental disabilities and traces the changing attitudes towards the treatment and care. South African trends have followed international trends and the early care of mental patients in South Africa closely mirrored the British experience. Some terms used in this chapter would now be considered to be offensive. However, they are used to illustrate the prevailing attitudes at the time, towards people with mental disabilities.

THE DAYS BEFORE THE ASYLUM

One of the most prominent writers in psychiatry, Scull (1993) wrote that at the outset of the mid-eighteenth and mid-nineteenth centuries the mentally ill were not treated differently to any other type of deviants. They were included in a much larger group considered to be lacking in morals. This group included the poor and the helpless as well as beggars, petty criminals and the physically challenged. In medieval England, the poor classes relied heavily on a disorganized custom of Christian charity and almsgiving whilst wealthier individuals were cared for privately by their families. Efforts were also made to keep the mentally ill in the community, and this was done by providing their relatives or others who were prepared to look after them with permanent pensions in terms of the "Poor Laws" of the time. According to MacDonald (1981, cited in Scull, 1993:11), *"In only a small minority of cases was any effort made to*

relieve the family of the burdens the insane posed by gathering lunatics together in institutions."

According to Scull and Jones (1979; 1955 cited in Carrier and Kendall, 1997) up until the seventeenth century, Bethlem was the only specialized facility for the so-called 'lunatics'. In other parts of the country, the mentally ill who presented a threat to the social order or had no friends or family for support, found themselves cared for, in one of the small medieval hospitals that also catered for *"the sick, aged, bedridden and diseased"*, (Scull,1993:p11).

THE ERA OF THE ASYLUM

Smith (1999) noted that during the eighteenth century there was an important growth in both the private and public provision for the care of the mentally ill. There was an increase in private 'madhouses' being opened around the country to cater for the growing demands for confinement of the relatives of the wealthy who were unmanageable at home.

Smith (1999) further indicated that the move to create public subscription asylums arose because of the concern of abuse of the mentally ill taking place in some of the 'madhouses' as well as the lack of services available to the poorer classes. London's, St Luke's asylum emerged in 1751. This was followed by asylums in Newcastle in 1764, Manchester in 1766, and York in 1777. Other asylums emerged in regional centres such as Liverpool, Leicester and Exeter. Smith (1999: 34) explains:

> *"These 'lunatic hospitals' were set up on similar lines to the subscription infirmaries being developed in major towns. Their projectors emphasized their philanthropic intent, in comparison to the commercial motives of madhouse proprietors. The trustees of Manchester Infirmary in 1763, for example, sought to offer a place where the 'terribly afflicted' relations of people of 'middling Fortunes' could be preserved 'from the Impositions of those who keep private Mad-houses'. An element of active competition with the private sector was clearly envisaged".*

The intention of creating the asylums was mainly to accommodate for people whose families could not afford private care. In the late eighteenth century there were noticeable changes in the trends for the demand of institutional care. Parish officers were increasingly required to remove paupers who were alleged to be mentally ill as their families were unable to care for them and there were also those who were unmanageable in the poor house. Some of these mentally ill persons made their way into public asylums. However, due to the limited capacity of these asylums, large numbers of the mentally ill were sent to private madhouses. The requirement of the parish authorities for the placement of the mentally ill from the pauper class brought about a new factor into the subject of care. Owners of 'madhouses' contracted with parish authorities to accept paupers into their care at tariffs far less than those received for private patients. However, this involved differences in the level of care and accommodation that was provided. The need to establish county asylums arose from the seeming success of the eighteenth-century public subscription asylums. Reformers felt that they illustrated a distinct option to that of the private 'madhouse', which was progressively seen as undesirable and exploitative.

Based on the conclusions deduced by the select committee in 1807, legislation emerged in 1808 (Smith, 1999). The report recommended that asylums be big in size to promote cost-effectiveness but should not have more than 300 residents. The Act passed in 1808 ordered that asylums be erected in an environmentally healthy environment, with an adequate water supply and also conducive to receiving regular medical assistance. However, issues pertaining to finances, admissions and discharges were left to the discretion of the Justices of the Peace. Faced with the task of constructing and administering these facilities, local magistrates modelled their institutions on existing asylums. Some even employed superintendents, who they got to bench mark procedures with an older asylum. Others ascertained information via correspondence with people that were administering existing charity asylums or took the assistance provided by 'madhouse' keepers. The care received by patients in the new asylums relied on

which older institution their asylum was replicated on, and in many cases, there was poor management and brutal methods (Scull, 1993).

Reform of custodial care

"The madman was often treated no better than a beast; for that was precisely what, according to the prevailing paradigm of insanity, he was. In becoming crazy, the lunatic had lost the essence of his humanity, his reason". This quote from Scull (1993:p92) reflects the predominant views of the seventeenth and eighteenth centuries and it was these views that nineteenth century reformers and society as a whole wanted to discard. Reformers did not see the mentally ill person as an animal removed of all remaining qualities of humanity but rather as a person who lacked self-control and order. They felt that the deficient qualities could be re-instated so that the person could function as a clearheaded and lucid person (Scull, 1993).

Scull (1993) explained the reformers were lucky that 'madhouse' keepers were looking for ways to manage and treat patients. This indicated the possible eradication of the inhumane traits of the modern asylum. However, it was the establishment of the York Retreat in 1792 that became reknowned for its 'moral treatment' of its inmates and was consistent with the idea of reform.

An investigation into York Asylum uncovered evidence of serious wrongdoing. Patients were ill treated and some had been raped and murdered. Records had been forged to hide deaths. Chains and other forms of restraints were used and conditions of filth and neglect were uncovered. Following the mysterious death of a patient from the Quaker community at the York Asylum, a local tea and coffee merchant, William Tuke, pushed his community to establish an asylum for friends that lost their ability to reason. Neither corporal punishment nor chains were tolerated in the York Retreat. Less offensive types of restraint could be required to avert bodily harm but only as an ultimate resort. The institution halted the use of 'gyves, chains, and manacles' and this was viewed as evidence that

the mentally ill could be handled without harshness and cruelty. From its buildings to its living arrangements, the Retreat promoted a comfortable and familial environment that supported the efforts of individuals to reaffirm their ability for restraint from engaging in harsh or cruel behaviour (Scull, 1993). The retreat proved to be a success with a large proportion of cases being restored to sanity.

Scull (1993) further explained that in 1814, Edward Wakefield another member from the Quaker community, publicized his plans to establish a 'London Asylum' that was to be modeled on the York Retreat. This resulted in a committee being created to prepare for the development. Part of the planning included a re-look into the existing services provided for the mentally ill in London by examining Guy's hospital, St. Luke's and Bethlem. Appalled at the cruel and inhumane treatment of patients at Bethlem, Wakefield realized that significant reform would not be achieved by creating another asylum like the York Retreat, and instead he rounded up a group of concerned MPs and revisited Bethlem with them. The MPs pushed for a Parliamentary investigation into the conditions that prevailed in 'madhouses' and charity asylums. The resultant effect was the authorization of a Select Committee in 1815 and the initiation of the inquiry (Scull, 1993).

The inquiry helped to shed light on what the reformers wanted to accomplish. Despite ascertaining that patients were abused and maltreated in basically every type of institution that was investigated, the committee, as well as those who informed the public of the findings, saw this as proof of the need for the creation of more institutions which would operate under direct public control, and a system of inspection and supervision of all facilities that cared for the mentally ill (Scull, 1993).

A move backwards
The ensuing years saw the construction of large psychiatric institutions. According to Scull (1993), the emergence of these huge institutions resulted in

the near death of individual attention to patients. Patients' days were filled with routine monotony that was ill suited to mental healing, and their activities were organized in order to suit the timetable and the routine of the asylum. Investigations into the asylums revealed them to be *'simply a larger prison [with its']* inmates sitting listlessly and depressed in the lengthened corridors... Mocked [by surroundings] of which they took no heed'* (Francis Scott cited in Scull, 1993:p287). Many of the asylums had one or two wards that were occupied by the 'better behaved' patients who were likely to have a short stay in the institution. These wards offered a less depressing environment compared to that provided to majority of the other patients. Discharges of patients were carried out either by order of the medical superintendent or on the request of family (Wright, 1999).

In the words of Rollin (2003:p2)

> "The newly built asylums were.... travesties of those dreamed up by the early reformers: they were huge, housing 2000 and more patients; they were crowded, uncomfortable and therapeutically stagnant...................The patients the staff had to deal with..................in addition to bona fide patients, an assorted ragbag of misfits: people with varying grades of learning disability; those addicted to drugs and alcohol, either acutely or chronically disturbed.......... vagrants; the aged who had become an embarrassment to their kin; pregnant single women who had been cast out by their relatives; and anyone who by hook – and not infrequently by crook – could be squeezed into whatever the law required to be 'certified'. Voluntary admission was not an option."

Moves to prevent the wrongful detention of individuals

According to Jones (1972, cited in Carrier and Kendall, 1997:p6), the *"public view"* on the detention of individuals in asylums was reflected in the success of two novels written by Charles Read and Wilkie Collins. These books had a story line where the wrongful detention in 'private madhouses' had a crucial role. Carrier and Kendall (1997) explained that if this was in fact the *"public view"*, then it must have contributed in supporting a legal approach that protected people from being wrongfully kept in asylums. The Lunacy Act of 1890 emerged which

brought about laws that coordinated asylums and compulsory care (Stewart, Mind Information unit 1998, 2003).

Carrier and Kendall (1997: p7) explained that the care of the mentally ill at the end of the nineteenth century in comparison to the beginning had been depicted by Scull (1979) in his comment that insanity was changed *"from a vague, culturally defined phenomenon afflicting an unknown.......into a condition which could only be authoritatively diagnosed, certified, and dealt with by a group of legally registered experts"*.

Amongst the advances made in the nineteenth century was the legal interest in the well being of patients as well as an important function of the medical profession in defining and redefining mental illness (Carrier and Kendall, 1997). These two writers also wrote that the nineteenth century also saw an undertaking to construct asylums that would be better than the workhouses or private 'madhouses'.

THE MOVE FROM INSTITUTIONAL INCARCERATION

Carrier and Kendall (1997:p8) explained that it was commented by the Royal Commission of 1924-26 that the focus of the past had been *"detention"* but the focus of the future should be on *"prevention and treatment"*. It was also suggested that public funds be provided for care in the community. This followed a further recommendation three years later by the Wood Commission that there should be better use of all available forms of community care.

Voluntary treatment

The report by the Board of Control in 1918 recommended, treatment for a limited period without certification and this followed the opening of the Maudsley hospital in 1923 to voluntary patients. Provisions for voluntary treatment were made in the Mental Treatment Act, 1930 (Carrier and Kendall, 1997). There was a

gradual increase over the years in the rate of voluntary admissions. In 1932, seven percent of total admissions were voluntary however, this increased to 35 percent in 1938, and 59 percent in 1948 as indicated by Jones and Goodwin (1972; 1989; cited in Carrier and Kendall, 1997).

Development of a medical model in treating the mentally ill

Scull (1979) cited in Carrier and Kendall (1997:p7) mentioned that the patients treated in asylums were *"diagnosed as a uniquely and essentially, medical problem"*. The care of the mentally ill was seen as distinctly different from that provided to physical illness or caring for those who presented with physical illness (Carrier and Kendall, 1997). This understanding began to change in the early part of the twentieth century. A Report of the Royal Commission on Lunacy and Mental Disorder (1926, cited in Jones, 1960 and cited in Carrier and Kendall, 1997), suggested that there was no clear line of demarcation between mental and physical illness and there was a proposal that provisions be made in the general hospitals for the early detection and treatment of mental illness.

A further development was in the area of treatment modalities like electro-convulsive therapy, neurosurgery and insulin coma treatment that took place in the years between the two world wars. With better treatment and control of symptoms, it was only a matter of time before attempts would be made to move away from institutionalisation.

THE BEGINNINGS OF THE NATIONAL HEALTH SERVICE AND THE FORMULATION OF THE MENTAL HEALTH ACT, 1959

According to Carrier and Kendall (1997) in 1948 all the mental hospitals under the auspices of the local authorities became part of the National Health System. The new service consisted of a tripartite structure, which included the new hospitals, general practitioners and the local authority health service. Each had

its own budget and responsibilities. This system was criticized for its weaknesses in providing holistic care for people with mental illness.

It was further explained by Carrier and Kendall (1997) that new terminology relating to Mental Illness and Mental Deficiency in 1957 was recommended by the Royal commission. Examples of this terminology are *"mentally ill, psychopathic, and severely subnormal"* (Carrier and Kendall, 1997:p9). Carrier and Kendall (1997) further expanded that the report suggested that patients should be admitted to mental hospitals in a similar fashion as other hospitals that is mandatory confinement was only to be carried out if considered essential for personal or public safety. If patients have progressed to a point were they could return home and provided that they had a fairly stable home to go to, they were to be no longer detained as in-patients. At that stage, it then became the responsibility of the local authorities to provide residential care.

A new Mental Health Act in 1959 brought about further changes as it ensured that community care was provided by the local authorities (Carrier and Kendall, 1997). One of the recommendations by the Royal Commission which was significant but which did not find its way into the Mental Health Act as explained by Carrier and Kendall (1997) was that a specific grant be allocated to local authorities in view of the new principles of community care. The mental health grant continued to be part of the overall health grant and placed obstacles in the way of implementing community based care (Goodwin, 1989 cited in Carrier and Kendall, 1997).

Prior to the Mental Health Act of 1959 becoming law, a number of concerns were voiced. McDougall summed many of these concerns when he commented that even though it may be felt by some people that it is a 'privilege' for the mentally ill person to live in the community instead of in hospitals, it could lead to an insurmountable burden on family members and can prove dangerous if there is a

lack of support from professionals such as psychiatrists and social workers (McDougall, 1959 cited in Carrier and Kendall, 1997).

More reknowned were the concerns of Richard Timuss two years later, in his lecture presented to the "1961 Annual Conference of the National Association of Mental Health". He wondered if people were engaging in wishful thinking because of the civilized Mental Health Act. He challenged his audience to examine the realities of community care and he was concerned that community care will lead to a situation of *"transferring the care of the mentally ill from trained staff to untrained or ill-equipped staff or no staff at all"* (Titmuss, 1968 cited in Carrier and Kendall, 1997:p10).

Following these observations, the community care policy for mental health services made a concrete move a year later to do away with the old asylums.

THE FALL OF THE ASYLUMS

Carrier and Kendall (1997) provided a description of the details that led to the closing down of asylums. Following the implementation of the 1959 Mental Health Act, the British government embarked on a plan to close down asylums that were considered to be expensive and contained large numbers of individuals who did not require institutional care and infringed on the human rights of people (Carrier and Kendall, 1996; Robb, 1967; Martin, 1984 cited in Carrier and Kendall, 1997).

Between 1962 and 1990 there emerged a barrage of policy documents and commissions of enquiries which supported the idea of community care and tried to find ways to facilitate the closure of hospitals and promote the support and care of people in the community. These included; The Hospital Plan in 1962, Hospital Services for The Mentally Ill (Circular 71 of 1971); a White Paper Better Services for the Mentally Ill (DHSS, 1975), Consultative document of 1976,

Priorities for Health and Personal Social Services in England (DHSS, 1976);The Way Forward: Priorities for Health and Personal Social Services in England document of 1977 (DHSS, 1977), The Noder Report (DHSS, 1978), A Care in The Community Document compiled by DHSS in 1983, An Audit Commission Report in 1985 on community care, the Griffiths report in March 1988, Caring for People (DOH, 1989) and NHS and Community Care Act, 1990.

Some of the challenges in bringing about these policy changes included the integration of psychiatry into medicine and difficulties in creating a distinction between medical and non-medical fields of work due to overlaps in work. There was also a lack of assistance to discharged patients; they were left to their own devices (Carrier and Kendall, 1997). Through the Taps research, it emerged that community care in comparison to hospital care is no longer cost-effective. In fact, it ascertained that savings achieved through the closure of hospitals should be adequate to fund community care programmes (Carrier and Kendall, 1997). This supported the Griffiths report in March 1988, which advocated for 'ring-fenced' funding for community care services (Leff et al, 1995 cited in Carrier and Kendall, 1997).

Another important challenge reflected by the North East Thames Regional Health Authority (NETRHA) nine years after the decision to close Friern and Claybury psychiatric hospitals was the public and staffs' lack of understanding of the advantages of community care as well the reluctance to move from Friern hospital due to misinformation (NETRHA, 1992 cited in Carrier and Kendall, 1997).

Carrier and Kendall (1997:p18) wrote that *"poor understanding"* is one reason why people concerned with the quality of mental health services, anticipate a time when the comments made by McDougall (1959) and Timuss (1961) will have only a historical relevance and will not be contained in existing reflections (Carrier and Kendall, 1997).

MENTAL HEALTH SERVICES AND POLICIES IN SOUTH AFRICA

As mentioned in the introduction to this chapter, mental health services in South Africa have mirrored developments internationally. In this section, I discuss the development of institutional care in South Africa and trace the movement towards community care.

THE ESTABLISHMENT OF ASYLUMS IN SOUTH AFRICA

According to Emsley (2001), institutional medical care in South Africa commenced more than 300 years ago with the creation of a small hospital by Jan van Riebeeck. In 1711 the construction of the first hospital for the care of mentally ill persons came into being. This entailed an additional apartment to the new Cape Hospital in 1699 by Simon van der Stel. Later the Old Somerset Hospital became the first designated hospital for the care of the insane. However they were seen as unsuitable for the care of the mentally ill which resulted in Robben Island (previously used for prisoners) being transformed in 1846 into a hospital for lepers, lunatics and other patients who were chronically ill. By 1912, 500 mentally ill patients were accommodated at Robben Island. In this time other 'lunatic asylums' were built, reinforcing the isolation of mentally ill patients from the larger community. These new asylums included the Town Hill Asylum in Pietermaritzburg, Fort England Mental Hospital in Grahamstown, Valkenberg Lunatic Asylum in Cape Town, as well as the Pretoria Lunatic Asylum (Makepeace, 1969 cited in Emsley, 2001).

When the Union of South Africa was formed in 1910, there were eight mental health facilities providing care to 3624 patients. This rose to 13 government mental health hospitals in 1955 which catered for 17 881 patients. In 2001 when this article was compiled by Emsley, he indicated that there were 24 registered public psychiatric hospitals that cared for 14 000 acute and chronic mentally ill patients (Emsley, 2001).

The Mental Disorders Act was introduced in 1916. It was the first attempt at legislating the care of mentally ill persons. It did not stipulate any services for neurotic and personality disorders, alcohol dependence or learning disability.

MENTAL HEALTH POLICIES DURING APARTHEID

According to Burns (2008), the Mental Health Act No.18 of 1973 only promoted the control and treatment of patients. Similar to international regulations concerning mental health the main concern was the wellbeing and security of the community instead of the patients suffering with the mental disorders. By placing the community before the patients, it led to violation of patients' rights because the safety of the community was considered to be more important than the right of the individual. Suspecting individuals of suffering from a mental disorder was enough to have them certified to a psychiatric institution which was often, extremely far away from the patient's home. The certification procedure itself was open to abuse. Very often, ulterior motives including jealousy, personal prejudices and vendettas were behind the certification of patients. Certification was exploited as a form of confinement for political reasons to detain and quieten down protesters or individuals. Once certified, patients could do nothing except endure being in hospitals against their will for long periods. These patients had no way of ascertaining any help from the law.

Burns (2008) also explained that the previous Mental Health Act of 1973 strengthened the division of mental health services from general medical care. Services to mentally ill patients were separate and were not included in primary health care services. Due to this, it was not necessary for the general medical practitioners to accept any accountability for mental health. The outcome of this included troubled patients with grave medical conditions slipping through the system.

Burns (2008) indicated that another major disadvantage of this Act was the concentration of psychiatric services in urban tertiary psychiatric hospitals. These institutions were located very far away from the households and neighborhoods of most patients. Patients from rural areas were admitted to hospitals that were great distances from their homes, family and employment area. Little or no care existed in the community. Patients who entered the health system became powerless, alienated and stigmatized by the system. Whilst there existed well-meant individuals, the structure of mental health services and the Act *"meant that admission was a traumatic and damaging experience"* (Burns, 2008:p1). In terms of the Mental Health Act psychiatrists were central to the care of the mentally ill.

In the apartheid system, health services were fragmented and provided according to race. Some psychiatrists took part in setting up and implementing separate services for the different race groups. Many more psychiatrists protected them. However, most psychiatrists voiced their concerns but this did not prove to be loud enough (Allwood, 1997 cited by Emsley, 2001). The Society of Psychiatrists of South Africa made a number of declarations and protested at the time but members were not united in their anti-apartheid position (Emsley, 2001).

Psychiatry was the most condemned medical speciality by the international community. Psychiatric services were studied and criticized by overseas groups. A report compiled by the American Psychiatric Association in 1978 following the inspection of psychiatric services in South Africa, found psychiatric care for Black people disgustingly substandard to that provided for White people. They also concluded that these deplorable medical practices had caused needless deaths of Black patients and that *"apartheid has a destructive impact on the families, social institutions, and the mental health of Black South Africans"* (American Psychiatric Association, 1983 cited in Emsley, 2001:p6). This failure of South African psychiatrists to voice their concerns in unison about political abuses and

their complicity in perpetuating such abuses led to international condemnation and academic sanctions (Emsley, 2001).

In summing up, policies during apartheid, Burns (2008: p1) wrote *"Legislation prior to 2002 tended to reinforce the alienation, stigmatisation and disempowerment of mentally ill patients in South Africa."*

MENTAL HEALTH LEGISLATION IN A DEMOCRATIC SOUTH AFRICA

In 1994, a new democratic government was elected to ensure that the human rights of all South African citizens will not be violated again. The new government facilitated the formulation of the Bill of Rights within the Constitution of South Africa. The advent of democracy, the new constitution as well as the awareness of human rights saw the review of the Mental Health Act of 1973. Other factors such as improvements in mental health care and the increasing possibility of community-based care also contributed to the review of the Mental Health Act (Lifecare Document, 2004).

A new Act, The Mental Health Care Act (MHCA) no.17 came into being in 2002. The main aim of the Act was *"To provide for the care, treatment and rehabilitation of persons who are mentally ill; to set out different procedures to be followed in the admission of such persons; to establish Review Boards in respect of every health establishment; to determine their powers and functions; to provide for the care and administration of the property of mentally ill persons; to repeal certain laws; and to provide for matters connected therewith"* (Government Gazette, 2002: p2). It was also one of many regulations endorsed to free the country of its apartheid legacy (Burns, 2008).

The MHCA 2002 originated from the following important beliefs as written by Burns (2008):

1. People experiencing mental health problems are called 'users'

2. Services must offer care, treatment and rehabilitation to users unlike the previous Act that focused on control.
3. The human rights of the mental health care user (MHSU) are no different to the wellbeing of the general community
4. All practitioners working with health are referred to as mental health care practitioners (MHCPs)
5. There should be integration of mental health services into primary health care.
6. Users must receive treatment nearest to their homes or within their communities
7. Care, treatment and rehabilitation must be available to users, with minimal restriction on their freedom
8. MHSUs must have access to appropriate representation, information on their rights, and the right to appeal against decisions of MHCPs
9. Establishment of mental health review boards who will function as 'ombudsmen' in order to oversee the rights of the user, appraise decisions made in accordance with the Act and to consider appeals.

Freeman (2002) explained in support of the above points that an entire chapter in the Act describes the Rights and Duties Relating to users. Issues addressed include *"Respect, Human Dignity and Privacy; Consent to Care, Treatment and Rehabilitation services and Admission to Health Establishments; Unfair discrimination; Exploitation and Abuse of mentally disabled people; Determinations concerning mental health status; Disclosure of information; Limitation on intimate adult relationships; Rights to representation; Rights to discharge Reports and to have knowledge of rights."* Freeman (2002: p1) elaborates that this particular chapter and the Act generally was based on a number of international laws pertaining to mental health. The two main points in the documents which are fundamental to the Act are that decisions must be taken *"in the best interests"* of the MHSUs and *"in the least restrictive environment"*. He indicates that the intention of the Act is not to frighten health

workers working with MHSUs but to emphasize rights in light of the historical abuse of patients suffering from mental illnesses.

Concerns regarding application of the New Mental Health Act

Freeman (2002) explained that one of the main concerns in the new Act was agreeing on the conditions under which an individual can be admitted to hospital without their consent. The circumstance that has to be prevalent is that the individual has to be a danger to themselves or others or that admission is crucial for the safety of the person's reputation and finances. If it is found that the user requires further care and treatment, the head of the health establishment must admit the user within 48 hours. If, after completion of the 72-hour observation the user is assessed to be in need of inpatient care, the user must be transferred to a designated psychiatric hospital. Decisions regarding the provision of involuntary care must be forwarded to the Review Board who will in turn channel the details of this decision to the registrar of the High Court. Periodic reports are to be forwarded after six months and thereafter annually with reasons for continued care without consent.

In the event that the delay in the provision of care may lead to the demise of or harm to the MHSU or others or, if the MHSU may be responsible for the damage to or loss of property, *"a health care provider or a health establishment may provide care for 24 hours"* (Freeman, 2002:p5). If further care and treatment is necessary, an application must be completed. The Review Board must be made aware of such decisions (Freeman, 2002).

Application of Mental Health Care Act (MHCA) 2002: 72-hour assessment:

In terms of MHCA 2002, district hospitals were assigned a key duty i.e. 72-hour admission and assessment of MHSUs. Many problems have emanated from this. These problems are common in district hospitals throughout the country and

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relate to both the practical and operational aspects of instituting this prerequisite (Burns, 2008).

Burns (2008) defends the 72-hour observation by indicating that it provides an opportunity to rule out any medical reasons for behavioural or psychiatric disturbance. In the cases of substance intoxication or withdrawal, acute trauma, parasuicide and brief psychotic disorders there are a number of users who recover adequately to qualify for a discharge within the first 72-hours. With regards to this, Freeman (2002:p7) also indicated that it is not essential for these users to go as *"certified patients"* to a psychiatric hospital and suffer the stigma and loss of dignity that accompanies admission. Burns (2008) pointed out the third advantage of the 72-hour observation was that users can obtain care and treatment near their homes and communities.

Burns (2008) stated that grave problems emerged with the provision of the 72-hour assessments at district hospitals that contributed to unfavorable levels of care and tragedies. He explained that users are heavily sedated for the duration of the observation period resulting in the prevention of an acceptable review. Secondly, users who are highly agitated or psychotic are insufficiently sedated and difficult to manage in general wards thereby contributing to dangerous conditions. Thirdly, incorrect pharmacological treatments or the doses administered to control MHSUs' behaviour sometimes cause iatrogenic complications. Fourthly, poor assessments of medical conditions, and after being categorized as a psychiatric patient, users are then not provided with the routine examinations and investigations. Fifthly, there is a failure at district hospital level to complete MHCA forms.

Burns (2008) reiterated that the difficulties mentioned are applicable to all district hospitals around the country and does not refer to the Act's validity but rather to the actual application. He noted that there are infrastructural and functional

inadequacies that contribute to the practical implementation of the 72-hour observation. These include:

1. Insufficient facilities to contain disturbed and violent users.
2. Insufficient skills possessed by health workers in dealing with psychiatric patients.
3. A lack of understanding of the MHCA 2002 as well as the applicable forms.
4. Insufficient medications, lack of treatment protocols, guidelines and knowledge of referral options.
5. The unclear roles of the South African Police Services (SAPS) and Emergency Medical Rescue Services (EMRS) in the management of MHSUs as well as their (SAPS and EMRS) regular unhelpful involvement.

FROM LEGISLATION TO POLICY

In an attempt to implement legislation, a number of policy documents and guidelines have emerged. Of particular note are the following:

Strategic Plan (2003)

In anticipation of the Act, the KwaZulu-Natal Department of Health formulated a "Strategic and Implementation Plan for Delivery of Mental Health Services in KwaZulu-Natal." The plan was in line with the Act, which stipulated the framework for integrated mental health services at primary secondary and tertiary levels of care. The objective of this plan was to direct the implementation of the Act in this province (Burns, 2008).

This plan endorsed primary services to mental health service users at a community level in Primary health care (PHC), community health centers (CHC), and district hospital levels. General medical practitioners were now required to offer care, treatment and rehabilitation to MHSUs. Services were to take the form of "outreach to PHC and CHC, outpatient services, screening and follow-up, appropriate referral and provision of short-term inpatient care for a period of 72

hours (Burns, 2008). However, the implementation of the 72 hours produced many problems.

Burns (2008) went on to explain that secondary level of care would be available at regional hospitals. This will entail a psychiatric unit with dedicated beds for MHSUs. The team at the regional hospital will be inclusive of a psychiatrist, this team will be accountable for, in and outpatient services together with the provision of support and outreach services to clinics and district hospitals within that region.

Designated psychiatric hospitals will be responsible for tertiary care. Specialized services pertaining to forensic psychiatry, child and adolescent psychiatry as well as treatment of addictions and psycho geriatrics will be accessible at tertiary level.

The new regulations also require that all state departments inclusive of mental health providers contracted by the state must ensure all its policies support community based care (Freeman, 2002).

According to Bartlett & Wright (1999), in the 1850's men in the medical field were questioning the efficiency of larger 'warehouses" for the mentally ill. John Bucknill and Alexander Morison, believed that a policy of care for these service users should be flexible and therefore include both institutional and community options. In spite of the growing use of community care, a need has arisen for institutional care for a certain group of service users. This is supported by Payne (1999:p265) who stated, *"The role of the hospital and hospital based psychiatry continues to occupy a central role and for some groups at least, will continue to represent a significant feature of their lives."*

The Psychosocial Rehabilitation Policy (2006)

The psychosocial rehabilitation policy has been endorsed by the KwaZulu Natal Department of Health and it focuses specifically on psychiatric services in a holistic manner. The objectives of this policy are:

1. *"Reducing symptomology through appropriate pharmacology, psychological treatments and psychosocial interventions.*

2. *Reducing iatrogeny by reducing and eliminating, where possible, the adverse physical and behavioral consequences of the above interventions, as well as-in particular the consequences of prolonged institutionalisation.*

3. *Improve social competencies by enhancing individual's social, psychological coping and occupational functioning.*

4. *Reduce discrimination and stigma.*

5. *Enhance support to families with a member who has a mental disorder.*

6. *Creating and maintaining a long-term system of social support, covering at least basic needs relating to housing, employment, social network and leisure.*

7. *Empowering carers and users through psycho education programmes, active involvement in the programme and encouraging advocacy"* Psychosocial rehabilitation policy (2006:p17).

The proposed policy for psychosocial rehabilitation by the Kwa-Zulu Department of Health will hopefully seek to bridge the gaps in service delivery that are currently experienced. One of the main gaps in services relates to the need for different housing options for the mentally ill which will be in line with their level of functioning. As it has been recognized in other countries like USA and UK, South Africa has been no different in realizing the importance of suitable housing for MHCSU in their rehabilitation. This policy supports 'a real home' in the community as the final aim for individuals afflicted with mental illness. The health of mental health care service user is a social concern and it is important that the psycho-social rehabilitation programme is implemented with speed in order to benefit mental health service users and their relatives as soon as possible.

It is hoped that the cost implications will not affect the implementation of the psychosocial rehabilitation programme. As stated by Burns (2008), inadequate resources are one of the reasons that many problems are experienced with the new MHCA 2002. It has been further stated by other writers that one of the obstacles to providing appropriate community care in the U.K and USA is the lack of financial resources. However, it is the responsibility of political leaders as well as mental health administrators to ensure that adequate resources are available in order to ensure that the provision of the psychosocial rehabilitation programme is not comprised. This is supported by Carrier (1990) and Leff (1997) who stated that politically we need a climate that will be enabling and also where resources for mentally ill persons will not be seen as a burden on the economy. Leff (1997:p205) further promoted the concept of *"ring-fencing"* in that the funds utilized in the hospitals should be transferred with the mental health care service user and the services to the community. However, one wonders whether such a system will suffice within the South African context, where mental health care provided in hospitals were predominantly that of custodial care. The funds that have been utilized in hospitals may not be sufficient in terms of the services required for mental health care service user within the community.

Resolutions for improved services at district hospitals

Legislation is difficult to change and a number of people would agree that credible legislation should not be changed but accommodated, like the MHCA 2002 (Burns, 2002). He further stated that the Act must be accommodated for by improvising and careful planning which undeniably requires commitment from health care workers, administrators and Government. Mental care and services had been very badly neglected in South Africa and in order to change the services, support is required from political leaders as well as in terms of appropriate resources. Burns acknowledged the challenges faced in health however indicated that an acceptable standard of service to MHSUs should be available. Burns (2008) recommended the following ways of improvising current services at district hospitals:

1. Allocation of 2% of beds in general wards for MHSUs.
2. Availability of one seclusion room for the 72-hour assessment, for the treatment of violent and troublesome MHSUs
3. An outpatient clinic devoted to psychiatry.
4. At least one medical officer who is skilled in treating MHSUs and capable of applying the MHCA 2002.
5. There should be permanent psychiatric nurses and part-time occupational therapists, psychologists and social workers.
6. There must be outreach and support visits from regional or tertiary MHCPs.
7. There should be regular training on the MHCA 2002 as well as the use of the forms. Training should be recurrent every six months due to staff turnover as well as the complex nature of the act. Burns also viewed this to be the function of MHCPs at regional and tertiary level as well as the district office.
8. The formulation of treatment protocols for mental disorders at a regional level for dissemination to health workers at district and community level together with regular training on these protocols.
9. Secondment of medical officers, to tertiary psychiatric hospitals, for training in managing mental disorders.
10. Frequent training of local SAPS and EMRS employees on their roles relating to MHSUs and the MHCA 2002.
11. Distribution of MHCA 2002 and MHCA forms to all district and community health institutions.
12. Establishment of District Mental Health Forums in all districts involving health workers, administrators, representatives from SAPS and EMRS, community organizations and MHSU representatives.

CONCLUSION

This chapter commenced with an overview of the care of the mentally ill in Britain focusing specifically on the days before the asylum; the era of the asylum; going onto the move from institutional incarceration. It then touched on the beginnings of the National Health Service and the formulation of the Mental Health Act, 1959 before discussing the fall of the asylums. The second half of the chapter deals with mental health services and policies in South Africa, which concentrates on the establishment of asylums in South Africa, Mental health policies during apartheid, mental health legislation in a democratic South Africa and ends with a discussion on, from legislation to policy.

The next chapter focuses specifically on de-institutionalisation and community care; both from an international and South African point of view.

CHAPTER THREE

UNDERSTANDING DE-INSTITUTIONALISATION AND COMMUNITY CARE: LITERATURE REVIEW

INTRODUCTION

The previous chapter traced the development of services to people with mental illnesses. This chapter provides an overview of de-institutionalisation and community care. It begins by defining the concept of de-institutionalisation and then goes on to explain the process of de-institutionalisation and the factors necessary for de-institutionalisation. The importance of community care and the challenges inherent in this are then discussed. The chapter ends with challenges that have been identified in adopting de-institutionalisation and community care as the preferred treatment contexts in the country.

DEFINITIONS OF DE-INSTITUTIONALISATION

According To Bachrach (1997:p23), despite the extensive use of the word *"de-institutionalisation"* there is no standard definition. He indicated that this term has been understood *"in so many ways that it calls to mind the proverbial elephant: people are bound to judge this phenomenon according to which specific part of the beast they view and to how far away from the beast they stand"*(Bachrach, 1997:p23). De-institutionalisation will be viewed differently by a patient who has first hand experience of the system or a relative of the patient, compared to a hospital-based psychiatrist, a community nurse, a case manager, a program evaluator, or a legislator (Bachrach, 1997:p23) and she therefore suggested that de-institutionalisation be defined as *"the replacement of long-stay psychiatric hospitals with smaller, less isolated community-based service alternatives for the care of mentally ill people."*

This definition does not only refer to the process of reducing hospital beds even though this is the most common understanding of the term (Bachrach, 1986;

1987; 1997). However, this definition goes beyond reducing inpatient population in hospitals to encompass the provision of alternative services. To cut back on hospital beds or to close hospitals is a crucial part of de-institutionalisation but does not refer to everything that the concept includes.

THE PROCESS OF DE-INSTITUTIONALISATION

Initial policy statements in the United States emphasized that de-institutionalisation includes three separate processes (Bachrach, 1976; 1997). Firstly, mental health service users are discharged from the hospital. Secondly, new admissions are reduced and thirdly, there will be the development of accessible and appropriate services in the community. However, an assessment of de-institutionalisation reveals that the first two aspects have been implemented at a much faster rate than the third. This means that the critical aspect of providing appropriate and accessible alternatives in the community in place of hospitalisation has lagged behind and has not been developed to counter the effects of the first two components. Unfortunately, South Africa is no exception to this finding, and definitely has major shortfalls concerning the development of accessible and appropriate services in the community.

Studies have also shown that when all three aspects of de-institutionalisation are concurrently implemented people with mental illness benefit immensely. The benefits have been in terms of the improved quality of care that they receive, and the mental health care service user have indicated that they were more satisfied with their lives as compared to when they were inside the psychiatric hospitals (Warner, 1995; Bachrach, 1997). Some mental health service users, despite their mental illness have achieved some 'normalisation' in their everyday activities. Some lived on their own, there were others who were gainfully employed, and such achievements were few and far between prior to de-institutionalisation.

However, there were instances where in spite of community care being well planned and adequately funded some mental health service users have not done well. Shepherd, (1984), Wing and Morris (1981) and Bachrach, (1999) indicated that mental health service users found it difficult to maintain themselves in the community. Some of the other problems they encountered were easy access to chemical substances including alcohol which worsened their symptoms and affected the progress they could have made. Furthermore the severe fragmentation of services, the resistance from the community, the lack of sufficient and adequate housing opportunities proved to be a problem in providing appropriate residential placement for these mental health service users, although it is acknowledged that housing is essential for the success of community-based care (Bachrach, 1994; Carling, 1993 cited in Bachrach, 1997). Another difficulty that arose was the constant change in terms of mental health service users' needs and service delivery practices as well as the uncertain political support for the improvement of mental health services (Bachrach, 1991 cited in Bachrach, 1997).

Nevertheless, a need to understand the complexities involved in community-based care has emerged and this is a positive. According to Bachrach (1997: p28) the gift of de-institutionalisation has been the *"heightened awareness of the humanity and needs of mentally ill people."* There is also a bio-psychosocial understanding of mental illness i.e. how the mentally ill are affected by the relationship of the biological, psychological and sociological events in their lives (Eggel, 1977; Bachrach, 1997). This bio-psychosocial understanding dictates that the biology of mental illness, the sociological context of care and most importantly individual situations, needs and hopes of mental health care service user are taken into account when mental health services are planned with and for them (Hartmann, 1992; Bachrach, 1997).

There have been lessons learned from the bio-psychosocial viewpoint of de-institutionalisation that is paramount to the provision of a *"humane and sensitive community mental health care"* (Bachrach, 1997:p29).

FACTORS NECESSARY FOR SUCCESSFUL DE-INSTITUTIONALISATION

The lessons learned as illustrated by Bachrach (1997) are as follows.

An awareness of secondary consequences of de-institutionalisation
It is important to acknowledge that de-institutionalisation is more than just changing the locus of care. A social process is associated with secondary consequences. Not only is it an important geographical event but it is a continuing process that carries subtle implications. To be more specific it is an imperative process of continuing social change i.e. of movement retreating from one orientation of care towards another, which is radically different but has an insurmountable impact on the lives of mental health service users.

Today, de-institutionalisation impacts on the lives of individuals who continue to use psychiatric hospitals by decreasing the period of their stay in these facilities. Often discharging mental health service users becomes an end in itself that sometimes overrides clinical concerns. De-institutionalisation affects the people who do not utilize psychiatric hospitals but who could have done so in another era. These are individuals whose admissions have been prevented or diverted completely.

The success of de-institutionalisation cannot be measured in terms of the reduction of mental health service users in hospitals, because this will cause those mentally ill persons who never enter hospitals to go unnoticed (Bachrach, 1978 cited in Bachrach, 1997). Mental health service users who end up on the streets, in jails and prisons may also be ignored. It has now been reported that there are more mental health service users in jails and other correctional facilities than in public psychiatric hospitals.

Service planning should be tailored and individualized according to needs

De-institutionalisation has clearly shown there is a need for highly individualized care for mental health care service users, as they make up a diverse and heterogeneous group of people (Sartorius, 1992 cited in Bachrach, 1997). Mental health service users differ in their ability to tolerate stress and change. There is also a variation in the kinds of programmes that will be suitable for their needs, example, whether they can live alone or are more suited to group residential homes, the level of psychiatric interventions or care they require and their ability to work and the kind of employment opportunities that would best suit them i.e. sheltered, supported work or competitive employment.

Prior to de-institutionalisation there was a tendency amongst service planners to consider all mental health service users collectively and to ask what has to be done with the mentally ill? However, a focus on rehabilitation and individual need has emerged with de-institutionalisation and the question rephrased to *"What may we do for this particular person who suffers from a mental illness?"* This represents a concrete and significant move in the care of the mentally ill (Bachrach, 1997: p30).

Access to hospital care should be facilitated

It is vital to ensure that access to hospital care for mental health service users who require it, is facilitated and provided for as long as they need it. In the initial years of de-institutionalisation it was believed by many that if the counter therapeutic practices in psychiatric hospitals could be eradicated, the need for hospitals will be completely removed. In view of this, planning for community services was on the supposition that extensive resources for in-patient care will never be required in future.

This was unfortunate because it has been shown that just like people who suffer from somatic illnesses there are mental health service users who do need hospitalisation (Bachrach, 1997). According to Bachrach (1997), the number of MHSU requiring in-patient care, and the circumstances surrounding their

admission is reliant on what alternate community services are offered. It is clear that less people will need hospital care in places that provide an entire range of excellent and integrated community services. However, it is known today that the community is not necessarily the kindest treatment place for mental health service users at all times and that accessibility to hospital care for mental health service users who need it for as long as they require it, is absolutely crucial to the success of de-institutionalisation.

Services must be appropriate to culture

It has been observed that mental health programmes that are successful in a particular time and place are not necessarily successful in another, unless definite efforts are made to adjust the program to fit in with the culture of that particular place (Bachrach, 1988 cited in Bachrach, 1997). Therefore, it is essential that services are culturally appropriate. For example, it makes sense to plan services differently for rural and urban areas. There may be significant difference in these places in terms of the range of the quality of facilities as well as the effectiveness of the social support networks. Often there are obvious differences in attitude with regards to the use of mental health facilities (Sullivan, et al, 1996 cited in Bachrach, 1997). This point was definitely considered in the policy for psychosocial rehabilitation in Kwa-Zulu Natal,

> *"Each rural and remote region of South Africa is unique. Consequently, the barriers and opportunities for implementation of psychiatric rehabilitation services vary. There are three main issues for service provision in rural and remote areas; population needs, geographic factors and resources. Flexibility in service models will continue to be required to ensure that appropriate services are provided in rural and remote areas of the KZN Province"* (Psychosocial Rehabilitation policy, 2006:p20).

However, cultural concerns are not only that of urban, rural residence or ethnicity but extend to other social factors that must be taken into account when planning

services. For example, mental health service users who have been in psychiatric hospitals for long periods of time may have learnt to communicate to caregivers in stereotyped manners that will impact on how they approach and use the mental health system in the community (Schutt et al, 1993 cited in Bachrach, 1997). This is also applicable for persons who have spent long periods residing in homeless shelters or sleeping on the streets (Lamb et al, 1992 cited in Bachrach, 1997). This particular lesson therefore emphasizes that one-size-fits-all approach is not relevant for those people that are in need of community mental health care because they are unique individuals and must be considered within a specific cultural context.

Mental health service users must be involved in service planning
Mental health service users must be totally involved in the planning of services and the experiences as well as the values and personal goals of individual mental health service users must be recognized in the planning process (Heinssen et al, 1995; Sartorius, 1992 cited in Bachrach, 1997); this also requires that the mental health care service user be educated about his or her illness, symptoms, cause and consequences. As far back as 1976, Lamb indicated that individuals have an *"intact portion of the ego"* that must be engaged by clinicians to ensure that care is effective. This ego must be tapped and rewarded during treatment planning as it is not an unreasonable service planning guideline to *"ask the patient"* (Lamb, 1976 cited in Bachrach, 1997:p31).

There is also an extension of this lesson and that is to consult with the families of mental health care service user as well, when feasible. Family members often have expert knowledge that is not available to those who provide the service. Before de-institutionalisation, it was not widely believed that mental health service users and their families could or should be part of service planning. However, this has been provided for with de-institutionalisation so that the benefits of such involvement can be looked at and there is much acknowledgement of its effectiveness (Rogers, 1995 cited in Bachrach, 1997).

Services systems must be adaptable to change

The provision of services must not be restricted to fixed beliefs but must be open to change. This is reflected in the issue of housing for mental health service users. Some may live quite successfully in independent homes but there will be those who require structured and supervised residential settings. It is therefore imperative that service delivery for mentally ill persons is in keeping with their needs. (Wing, 1990 cited in Sammut & Leff, 1997) support this as they indicated that some mental health service users are too susceptible to live long in the community without the necessary support, and need asylum in the community. Yet the provision of affordable, supported housing said to be the foundation of community care has not kept up with bed closures (Thornicroft & Bebbington, 1989 cited in Sammut & Leff, 1997). Failure to do so will result in the needs of mental health service users being unfulfilled and therefore negatively affect their progress in the community.

Studies conducted in America have shown that some homeless mental health service users show more positive clinical outcomes when provided with the freedom to change residences in the early stages of treatment Dixon et al in (1993, in .Bachrach. (1997)); Harris and Bachrach in (1990, in .Bachrach. (1997)) and Schutt et al in (1993, in .Bachrach. (1997)).

The question may arise why should we as South Africans be interested in the experiences of countries such as America? *"The answer to this question lies in the fact that the problems associated with community- based care found in the United States are not limited to my country but shared throughout the western world, differences are often matters of degree, not substance"* (Schmidt, 1992; Thornicroft and Bebbington, 1989 cited in Bachrach, 1997:p22).

COMMUNITY CARE

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There is an overwhelming feeling that the institutionalisation of people with mental disorders promotes their segregation and isolation from the rest of society. This resulted in the institution replacing the family and community as the main provider of care. There is also the belief that community care is more effective than institutional care on the outcome and quality of life of individuals with chronic mental disorders. The notion is that care and treatment in the community results in greater chances of the mentally ill being rehabilitated. This has also lead to community mental health services integrating the care of a community's mental health needs with other health needs. The experiences of many countries concerning de-institutionalisation have established that good community care is essential to the success of de-institutionalisation.

Advantages of community care

According to Thornicroft &Tansella (1999: p12), "A community-based mental health service is one which provides a full range of effective mental health care to a defined population, and which is dedicated to treating and helping people with mental disorders, in proportion to their suffering or distress, in collaboration with other local agencies." Very important to this definition is that community-based mental health service should be an alternative and not be similar to the custodial pattern of care that is mostly utilized in psychiatric hospitals and clinics at an outpatient level, which offer follow up care that is usually limited to the management of medication (Tansella & Zimmermann-Tansella, 1988 cited in Thornicroft & Tansella, 1999). Lamb and Bachrach (2001) further indicated that when programmes are being planned they only consider the mental health care service user's immediate needs and does not take into account the future. It is extremely important that chronic mental health service users continue to receive services for an extended period, even indefinitely, preferably from the same service providers and mental health care professionals. Such information when put into practice has contributed to a better quality of life for mental health service users.

They also indicated that continuity of care was one of the lessons learned from the American de-institutionalisation process. The significance of continuity of care was ignored in the beginning of de-institutionalisation, when it was believed that with the lack of negative effects of institutional residence, there would be a disappearance of chronicity. Therefore planning services today often focus on the immediate needs of mental health service users and does not take into account the future, even though the needs of mental health service users suffer. It is critical that mental health care service user who require services over a long period of time or indefinitely receive such services and preferably from the same agencies and clinicians in order to ensure continuity of care.

Thornicroft and Tansella (1999) in seeking to provide a conceptual model for re-modeling mental health care indicated that psychosocial interventions for mental health care service user diagnosed with schizophrenia and their caregivers are established as effective (Mari & Streiner, 1996; Dixon & Lehman, 1995 cited in Thornicroft & Tansella, 1999). They went on to explain that there are seven aspects to psychosocial family interventions.

1. Creating an alliance with the caregivers of the mental health care service user.
2. Reducing the stress and burden on relatives in order to create a family atmosphere that is not unfavorable.
3. Empower relatives by improving their abilities to expect and resolve problems.
4. Decreasing the anger and guilt expressed by government.
5. Realistic expectations of mental health care service user performance to be maintained.
6. Encourage family to determine and maintain appropriate limits together while ensuring that there is some degree of separation when required.
7. Achieving the required transformation in mental health care service user behaviour and belief systems.

The above psychosocial interventions are used very rarely in routine clinical practice.

Horwitz and Reinhard (1997: p273) by looking at various studies carried out (Test and Stein 1980; Witheridge and Dincin 1985; Bond et al. 1988; Borland et al. 1989; Torrey 1990; Olfson 1990; Taube et al. 1990; Brown et al. 1991; Stein 1992; Burns 1993) found *"considerable evidence that clients in home-care programmes have fewer episodes and shorter periods of hospitalisation than those who do not receive these services. Participants in home-care programmes consistently achieve longer tenure of independent life in the community than non - participants. Clients in home-care programmes perceive a better quality of life."*

Sayce (2000:p11) indicated that Greenberg et al. (1994) found that in instances where relatives or friends lived with users that *"50 – 80% of relatives / friends said users contributed by doing household chores, shopping, giving emotional support, listening to problems, providing companionship and providing news about family and friends".*

Challenges experienced with community care

Contrary to studies that have found positive results, several studies illustrate the problems with community care. In a study conducted on the "quality of life of community based chronic schizophrenic patients in Penang, Malaysia", by Mubarack , Baba , Chin and Hoe (2003), it was found that majority of the respondents with chronic schizophrenia living in the community were not happy with the quality of their life. They faced many challenges specifically in the areas of place of living, daily activities, social relations, finance, work and general health.

Concerning place of living, many of the respondents lived with their families and were not happy with this arrangement. This study expressed the need for the creation of accommodation suitable for people with severe mental illnesses.

With regards to daily activities it was ascertained that majority of the respondents *"were not involved in any kind of rehabilitation programmes."* (Mubarak, Baba, Chin & Hoe, 2003: p583).

The participants in the study had problems socializing with people living in their social environment. This was attributed to the stigma attached to mental illness in Malaysia. The isolation of schizophrenics could be viewed as having a serious effect on their treatment outcome and symptom recovery. It was also identified that the readiness and ability of the community in recognizing and respecting people with mental illness is essential for any community mental health programme to succeed.

Participants who were employed reflected unethical and discriminatory work environments. In addition, respondents had trouble in accessing general health services despite the integration of psychiatric services.

The study reflected that in the community, the mentally ill are deprived of opportunities and there is a lack of prevention strategies to safeguard the rights of the mentally ill.

Discrimination is a major problem that is experienced by MHSUs in the community. There is a tendency to link mental illness to violence. According to The Mental Health Commission (1997 cited in Sayce, 2000: p7) *"Violence is firmly linked to mental illness in media coverage in both the US and UK, and also in New Zealand where, for example, journalists reported a 1996 mass murder in Tasmania in terms of the probable psychiatric disorder of the perpetrator. The fact, when it emerged, that he had no mental illness did not receive a similar degree of media attention".* Sayce (2000) indicated that if employers, neighbours and the 'general public' are to do away with discriminatory attitudes towards users then carers need to do the same. Relatives, partners, friends and neighbours of users require discussion and information that will enable them to

identify discriminatory views in themselves and others, and in rethinking and challenging them. It has been argued that, *"Users are most likely to shed their sense of shame if we succeed in attaining a society in which they are treated with greater value than at present "* (Sayce, 1998 cited in Sayce, 2000: p17).

A review of research on attitudes towards people with mental illness has found that people from all walks of life and all ages regard mental health care service user to be essentially tainted and degraded (Farina et al, 1992; Sayce, 2000).

Mentally ill persons are also seen to be very dangerous and the media has not helped to change this incorrect perception of persons who suffer from a psychiatric condition. These mental health service users are also portrayed to be lacking morals, to be shameful as well as irresponsible (Sayce, 2000). It has also been found in the US that 73% of prime-time TV characters who are shown as having psychiatric conditions are also portrayed as being violent. Characters displayed as mentally ill, were hugely portrayed as villains rather than heroes when compared to other minority groups (Gerbner, 1990 cited in Sayce, 2000).

It has also been found that the media also overrides personal experience. A relative who visited a family member in a psychiatric hospital for more than 20 years and who never saw an act of violence still 'knows' that mentally ill people are generally violent (Philo et al, 1993 cited in Sayce, 2000). It has also been ascertained that 87% of people in America stated that TV was one of their main sources of information on mental health, compared with 51% who received information from friends and 29% from doctors (Robert Wood Johnson Foundation 1990 cited in Sayce, 2000).

It is sad that people who have mental illnesses are looked down upon and that mental illness is not considered to be like any other chronic disease such as diabetes or high or low blood pressure. However the researcher hopes that a screening in late 2007on **3 Talk with Noleen Maholwane. Sanqwa**, a television

talk show on SABC three, on stigma of mentally ill people is an indication that in South Africa the media will seek to eradicate the stigma attached to mental health care service user rather than contribute to entrenching the incorrect perceptions of people and in this way assist in changing the negative attitude that mental health care service users are inferior.

Work and vocational activities as an integral part of community care

Creegan (1995) as cited by Leff and Trieman (1997) provides an explanation of various schemes in North America, which confront this problem. In a federal government office in Ottawa, a community work project was put together. Mental health service users work together in a group under the supervision of an occupational therapist. They work with normal employees for a maximum of five 3-hour periods per week. If they are found to be flourishing, they are accommodated in individual positions that have more independence. This programme has been found to be very successful in enabling mental health service users to advance to placements in employment, college and community vocational programmes with 59% of mental health care service users having achieved this (Vanier & Rivard, 1991 cited in Leff & Trieman, 1997). This is an example of transitional employment, which exemplifies the belief that a certain percentage of mental health care service user will be able to work in the open labour market. However, supported employment, which is a more recent development, is based on the ongoing monitoring of workers by a trained supervisor. This then exerts a high demand on the mobile job support worker (Cook & Razzano, 1992 cited in Leff & Trieman, 1997). Another method of ensuring that mental health service users have opportunities for realistic work experience is the "clubhouse model". Initially developed at Fountain House in New York (Beard et al, 1982 cited in Leff & Trieman, 1997), it is the basis of the COSTAR programme in Baltimore (Thornicroft & Breakey, 1991 cited in Leff & Trieman, 1997). Negotiations are carried out by the staff with prospective employers on the premise that the job will be completed irrespective of the absenteeism of mental health service users. If a mental health care service user

is absent from work that person is replaced by another clubhouse member or a staff member if necessary. In the clubhouse, members are given opportunities to socialize and are provided with affordable meals together with a job that is part-time as well as at an entry –level. Despite being established for 30 years, this model has only of late used in the UK.

Another alternative is to establish cooperatives managed by mental health service users for mental health service users. However, for this to be successful there must be provision of a service or the production of goods that are required by the public. Example, a courier service in Toronto, owned and run by previous psychiatric mental health service users (Creegan, 1995 cited in Leff & Trieman, 1997), a toy factory in Arezzo, Italy, that supplies wooden toys to a retail shop in the high street, a cafe in Kent, England (Blackthorn Trust) that receives organic food from a horticultural project.

These co-operatives have distinct advantages over both contract work as well as work on the open labour market. Although mental health service users do not have stress of a working environment, they are protected from the effects of lateness or absence. They have the company and sympathy of colleagues with similar difficulties. In addition, the projects have diverse positions with different levels of responsibility as well as initiative that are required. This is a big benefit for those mental health service users who have a higher education and is able to cope with a supervisory position as well as tasks that are different and more stimulating than the normal contract work. All of the above is indicative of the exciting and creative alternatives that exist to repetitive work activities that are generally offered in hospital vocational rehabilitation programmes. The process of making provision for mental health care service user provides an opportunity to move away from *"the custodial orientation to industrial therapy"* (Leff & Trieman, 1997:p199).

Access is required concerning support services, recreation and creative art, education and training as well as employment. However, an interesting question is, exactly what form would job opportunities for mental health care service users take , that is will the *"the custodial orientation to industrial therapy"* (Leff & Trieman, 1997:p199) prevail or will be consider moving away from this as is done in other parts of the world? It is very important for mental health care service providers in South Africa to consider the different types of work opportunities that have been created in other parts of the world and have proven to be successful. It is imperative that consideration be afforded to explore adapting these projects to our programme of community services and vocational rehabilitation.

DE-INSTITUTIONALISATION: THE SOUTH AFRICAN EXPERIENCE

As discussed in the previous chapter, a key policy initiative by the post apartheid government has been an attempt to decrease the dependence on long-term institutional care for people with severe and chronic disorders (Lazarus, 2005). According to Dartnall, Modiba, Porteus, and Lee cited in Lazarus (2005), the policy has instead promoted the development of care in the community. This has resulted in local advocacy groups and policy commentators echoing global concerns about de-institutionalisation. Lazarus (2005) indicated that the main concerns regarding de-institutionalisation is reflective of those expressed elsewhere. The concerns are:

Unsystematic discharges

The pressure to reduce beds may result in random discharges, with patients being discharged without a careful evaluation of their suitability for discharge as well as the availability of placement options in the community to which discharge will take place (Lazarus, 2005)

Lack of family and community preparation and support

Sufficient time and effort may not be put into preparing family members to accept and manage the discharged mental health service user in the

home environment. There may also be inadequate support for the family to assist in maintaining the individual in the community. This will include obtaining chronic medication, obtaining and retaining disability grants, as well as limited or no access to emergency assistance in the event of crises. Insufficient support to the family may be aggravated when family is not assisted with concerns, fears and prejudices of neighbours and the community or when family is not assisted to acquire support from available resources. The same concerns may apply to other placement options like non-governmental organizations, especially if they are not experienced in managing individuals with mental disorders (Lazarus, 2005).

Insufficient community resources

The availability of community resources may be crucial in lessening the burden of caring for an individual with a chronic mental disorder. The resources would include day care, workshops and drop-in-centers that are easily accessible. Scarce resources may contribute to unsustainable placements (Lazarus, 2005).

Lack of continuity of mental health care

If there are no follow-up services in the community, the chances of relapses are greatly increased. It may prove difficult to arrange re-admissions and this could result in greater reluctance on the part of everyone concerned to use community placement again (Lazarus, 2005). However, in the UK in 1990's, the community care system was in a crisis to an extent where it was ensured that community support and treatment was afforded to those who were in most need and not all those in need. Studies also concluded that there was a growing shortage of care for individuals with *"severe and enduring mental health problems"* (Payne, 1999:p261).

Revolving door syndrome

It is generally felt that the aforementioned factors may contribute to a pattern of revolving door admissions and discharges. This will result in patients not being adequately treated in hospital nor successfully integrated into the community (Lazarus, 2005). Payne (1999) stated in a study of patients caught up in the revolving door of admission and discharge showed that although most of them lived in independent accommodation, they lived alone, had no paid work and under poor conditions. Although they were in contact with mental health professionals, they received little daily support. The media was used to communicate that community care was not meeting the needs of these patients.

Neglect and abuse of mental health service users

One of the concerns is the possible neglect and abuse of mental health service users both within their families as well as in other placement options, especially when there are limited resources for monitoring placements. In South Africa, a specific concern is the abuse of the mental health service users' disability grants (Lazarus, 2005).

Accommodation

Lazarus (2005) indicated that housing for everyone in South Africa is still a far-away dream for many South Africans. According to "a new housing policy and strategy for South Africa" written in 1994, 61% of urban households live in formal housing or share formal housing with other families, 1.5 million urban informal housing units are in existence, 5.2% of households live in hostel accommodation and 13.5% of households (approximately 1, 06 million) reside in squatter housing countrywide. It was estimated that around 150 000 families per annum resort to this type of housing. Of the 17.1 million people approximated to live under the poverty line, two thirds live in the rural areas where there is a combination of formal and informal housing. However, both these sectors experience common problems of inadequate water and sanitation. In view of this,

people with chronic mental disorders are even more unlikely to access even the most basic of shelters. According to Bartlett & Wright (1999:p16) *"At the close of the twentieth century, insanity is associated in the public consciousness with homelessness seen as the visible failure of community care."* Horwitz and Reinhard (1997) also saw a major problem, in the provision of home care programmes to persons with serious mental illness, arising when their clients are not likely to have homes.

Burden on caregivers

De-institutionalisation has also resulted in the burden of care for the severely disabled service users, falling largely on individual families (Hatfield, 1989; Cook.et al, 1994; Breakey, Flynn, Van Tosh, 1996). Many service users discharged from in-patient care return to live with their families who are expected to replace their own homes with everything that was provided in the institutional setting. In most cases, parents are the primary caregivers. These are predominately women aged 65years and older. Most of them do not have adults in the house to assist with providing support. Some also indicated that relatives lived a long distance away.

A great demand is made on caregivers, which results in a critical need for support and assistance. They require assistance in the management of the illness, crisis management, and help with daily living skills, assistance in forming and maintaining social relationships as well as in finding productive activities during the day (Steinwachs et al, 1992 cited in Breakey, Flynn and Van Tosh; 1996).

Scull (1993) also explained that when families tried to care for their relatives who had been discharged from mental hospitals, they experienced a lot of problems in coping. They were forced to cope in light of the authorities refusal to attend to their requests to re-admit their relatives.

Kritzinger & Magaqa (2000) wrote that a number of burdensome responsibilities endured by caregivers emerged. What was also important was that the characteristics of the caregivers were similar to other studies conducted wherein it was ascertained that MHSUs caregivers tended to be predominantly females, and aged parents. The problems that the caregivers in this study experienced were the patients' refusal to comply with medication. Some families respond with threats of re-admission to overcome this problem while others are too afraid of the MHSU to try to achieve compliance, or portray feelings of indifference which maybe due to their own ignorance in understanding the importance of MHSU complying with medication. Caregivers spend huge amounts of money seeking assistance from traditional healers to cure their relatives. They were further stressed by having to be alert all the time to ensure that the mentally ill patient does not have access to dangerous materials such as matches, paraffin or petrol. Added to this is children's lack of understanding of the mentally ill cause them to be cruel in their behaviour towards this vulnerable group by making fun of them.

Kritzinger & Magaqa (2000) also found that in caring for the mentally ill relatives caregivers experience difficulties such as exploitation. They make sacrifices that often result in social isolation as they are unable to participate in social activities due to their caregiving responsibilities, financial problems, as well as feelings of embarrassment when MHSUs present with inappropriate behaviour such as *"undress or urinate in public, leave the house naked, masturbate and bath in public, spit on the floor, pull at women's dresses, beg money from strangers and pray for caregivers at church services"* (Kritzinger & Magaqa, 2000:p305).

The concerns outlined above must be viewed in relation to the system of mental health care inherited by the new South African government in 1994 together with the resources available and the constraints on transformation (Lazarus, 2005).

Lazarus (2005) further explained that the strategy followed for de-institutionalisation in Gauteng resulted in significant reductions in chronic beds as well as significant increases in community-based residential and day care. Community based organizations that had been offering services on an informal level had been licensed. There was an establishment of new non-governmental organisations (NGOs) whilst the capacity of existing non-governmental organisations was increased.

New NGOs were funded on condition that they correct the racial inequalities. Subsidies were increased annually however, they were still low. A programme was implemented to monitor services provided by NGOs and to provide training to improve the quality of care. However, some of the outcomes of the de-institutionalisation in Gauteng indicated a lack of information and review. Case reports from different service providers reflected that there were satisfactory adjustment to living with families or in an NGO. Preparation of mental health service users and families was not done adequately. Some mental health service users were inappropriately discharged.

Community care was also affected by staff constraints and attrition, which contributed to decreasing the ability of community psychiatric services to provide continuity of care and support services to family as well as NGOs. The extent of community-based care was limited and as a result placed limitations on discharges. Stigmatisation of psychiatric disorders contributed to problems in arranging placements in the community. Inter-sectoral co-ordination remains inconsistent.

Another South African study by van Rensburg (2005) found that various factors affected the outcome of a long- term service user in the community. These factors included individual level of functioning, compliance to medication, family and community resources etc. He found that it was difficult to select, prepare and anticipate according to current review processes that placements of long-term service users in alternate settings will be successful. MHSUs that were unstable and relapsed resulted in unsuccessful placements. There were also very limited community placements for the age group 40-60 years. The main reason for family refusing to accept responsibility for the care of MHSUs was their inadequate emotional, physical and financial means.

Van Rensburg (2005:p103) questioned the ability of the mental health system in South Africa to ensure that there is a *"distinct and applicable selection criteria"* to assess long-term service users for discharge and re-integration into the community. He indicated that there must be, sufficient supervised facilities, mental health professionals in alternative facilities or programmes, conquering of fragmentation of services after discharge and the availability of an adequate budget in order to implement policy and a system to monitor the outcome of these policy documents.

DIFFICULTIES IN PROVIDING COMMUNITY CARE

One of the distinct aims of the National Department of Health is to ensure accessible, equitable, adequate and appropriate mental health services for its citizens and in 1995 there was a move to shift the emphasis from hospital to community- based service provision by integrating mental health services into primary health care. Despite being politically necessary, it was also observed to be morally right (Freeman, 1998 cited in Emsley, 2001). However, the limitations of funds hampered this process (Emsley, 2001). This situation was not unique to South Africa as was indicated by Burns (2008) when he commented that other countries also had trouble in the implementation of Acts in insufficiently funded

and poorly planned situations. He referred to the situation in USA during the 1960s whereby large numbers of long-term mentally ill patients were released from psychiatric facilities with very little development of services in the community, which led to patients becoming homeless or imprisoned. Burns (2008:p48) also related this to the discharge of chronic psychiatric patients in the UK, which was also problematic during the 1980s but carefully planned for, with its *"care in the community policy"*. Change to a mental health approach inclusive of prevention and promotion and an extension of the service beyond that offered to the chronically mentally ill, has to be accomplished by using the resources available. Mental health integration into primary health care services has been progressing very slowly and has been impeded by the massive clinical loads of PHC workers and their insufficient training in mental health. Patients with psychiatric problems are not recognized and treated. Disruptive and psychotic patients are being treated by psychiatric hospitals (Emsley, 2001).

There is a severe lack of services in the rural areas (Lee et al, 1995 cited in Emsley, 2001). There is insufficient management of conditions such as epilepsy and learning disability, which reflects that people experiencing anxiety, mood and other non-psychotic disorders are not seeking help or using alternate therapies like traditional healers (Behr and Allwood, 1995 cited in Emsley, 2001). There has been a shift from the focus on, caring for the chronic mentally ill patients in the past, to preventive and promotive features of mental health. There is also progress to provide adequate services to patients who are not severely ill. Services to child and adolescent psychiatry are under par and there are limited staff and facilities for old age psychiatry and neuropsychiatry.

There is a marked shortage of registered psychiatrists in the country. There are not enough psychiatrists being trained and many also opt to leave the country once they qualify. There are only 429 registered psychiatrists for a population of approximately 44 million, of which, only 73% are currently practicing in the country (Flisher et al, 1997 cited in Emsley, 2001). Problems associated with

psychiatrists include their uneven distribution in the country, their large clinical loads and poor pay compared with their counterparts in European countries. In the state sector, psychopharmacology is the main type of treatment (Emsley, 2001).

According to Emsley (2001) amongst the challenges that face South African Psychiatry is finding ways to include technological advances into public services. Acquiring new psychopharmacological agents for use in anxiety, mood, psychotic and other disorders, costs greater and their availability is therefore limited in the public sector. Policy makers are also not convinced of the effectiveness of the new advances. Previously there was a provision of reasonable services by psychiatry however, psychiatry is now in competition with other medical specialities for a suitable piece of the health budget.

Changes in demographics and their influence on psychiatry should be taken into account when planning services in the future. Firstly, the age of populations in developing countries is increasing; this will result in age-related disorders being more common. Secondly, children are being orphaned by Aids at age 14 or younger. In 1999 there were 13.1 million children who fell within this age group, who were orphaned; 12.1 million came from sub-Saharan Africa (UNAIDS, 2000 cited in Emsley, 2001). There is a danger of available resources being overwhelmed with mental health problems associated with HIV. There is a need for policies to deal with these challenges.

There is a pressing need for more psychiatrists in state services, specifically in rural areas. The loss of psychiatrists through emigration as well as the lack of Black psychiatrists must be tackled (Emsley, 2001).

CONCLUSION

This chapter has considered the challenges of de-institutionalisation and community care. In the following chapter, the methodology of the study will be discussed.

CHAPTER FOUR
RESEARCH METHODOLOGY

INTRODUCTION

This chapter begins with an overview of the research process, explains the rationale for the choice of the research paradigm, describes the research design, sampling strategy, the methods of data analysis and how the research process was carried out in order to comply with the requirements for trustworthiness and authenticity. It concludes with the ethical issues that were considered as well as the limitations of the study.

AN OVERVIEW OF THE RESEARCH PROCESS

An exploratory-descriptive research design was used. The researcher interviewed six family members and four Mental health service users by means of in-depth interviews. Interviews were undertaken from March 2007 to November 2007. The interviews were held to explore the experiences of mental health service users (MHSU) who had been discharged from Ekuhlengeni Care Centre as well as experiences of their families.

RESEARCH PARADIGM

This research study aimed to gain a holistic understanding of the experiences of mental health service users and their families. A qualitative research paradigm guided the study and was considered relevant for this research study for several reasons.

Qualitative research allowed the researcher to see the world through the eyes of the service users and their families, specifically in relation to the services that they receive in the community, the challenges they face as well as their triumphs. This perspective encourages the researcher to " *put themselves in the shoes of the people they are observing and studying and try and understand their actions,*

decisions, behaviour, practices, rituals and so on, from their perspective"
(Babbie and Mouton; 2001: p271).

The emphasis of quality data is on the 'thick description' (Geertz, 1973; Bailey, 1997) i.e. in-depth description of actions. The data obtained from qualitative research is rich and powerful and due to the graphic description provided, it has a striking impact on the reader. The researcher is able to ascertain why things happen the way they do and assess causality as it occurs in a particular setting (Bailey, 1997). According to Bailey (1997), the 'lived experience' provides the research with the opportunity to establish the meanings people place on the events, processes and structures of their lives. As data is obtained and analyzed the information obtained from participants become clear and can be understood in relation to the world around them.

With qualitative research *"the emphasis is on developing and building inductively based new interpretations and theories of first order descriptions of events, rather than approaching the social actors with deductively derived research hypotheses"* (Babbie and Mouton, 2001: p273).

Qualitative research is conducted through intense contact with a real life situation that reflects the day-to-day life of people. In order to gain a holistic view of the topic to be studied the researcher will become a learner, learning from the participants as well as their surroundings. The researcher will attempt to understand the perceptions of the participants by being attentive, empathic and by abandoning preconceptions. This paradigm also explains how people understand, account for, act on and manage their day to day situations. Questioning and the collecting of information take place simultaneously (Miles and Huberman, 1994 cited in Bailey, 1997).

THE RESEARCH DESIGN

According to Marlow (2001) exploratory research is carried out when not much information is available on the topic being studied. In using the exploratory approach the researcher decided to use a 'descriptive strategy' as it was considered most appropriate with regards to providing valuable information that would answer the research questions. This design was used to explore and describe the experiences of adult mental health service users and their families upon discharge of service users, to their families in the Durban area, from Ekuhlengeni Care Centre from May 1999 to December 2001. It was exploratory in the sense that very few South African studies have focused on the experiences of service users once discharged from a long-term care facility. Also, in light of government's policy of de-institutionalisation and an emphasis on community based care, the study sought to gain an insight into and understanding of whether services provided in the community are sufficient to maintain the stable functioning of MHSUs (patients from Ekuhlengeni Care Centre were only discharged to relatives after they have been assessed to be functioning at a level where they can live in the community). The study was also concerned with ascertaining if community based care was implemented prior to ensuring that adequate resources and support exists in the community. In addition it aimed to describe these experiences of MHSUs and their families in detail.

SAMPLING STRATEGY

The intention was to do the sampling in two phases. The first phase was screening process of 20 MHSUs who have been discharged to their families in the Durban area. They were to be contacted to discuss their availability for participation in the study as well as to ascertain their level of functioning. Anybody undergoing a psychotic episode was to have been excluded. In the second phase, a random sample of 10 available participants was to have been obtained in order, to give all the participants an equal chance of taking part in the study. It was also planned that a family member responsible for the mental

health care user would be interviewed. This would have been a total 20 interviews. Where MHSUs would not be directly involved in the interviews whether due to their psychotic state or mental retardation, their families were still to be interviewed.

While an initial review of discharges indicated 20, further inspection revealed that the name of one person has been repeated and that another MHSU had not been in the institution for at least two years. This reduced the population to 18.

Telephone contact details were available for five MHSUs. They were contacted by telephone and four agreed to be interviewed by the social worker. The relative of the fifth MHSU informed the social worker that their relative had passed away two years previously and that they had placed their relative in an old age home immediately after his discharge, so he had in fact not spent any time at home.

There were no contactable details for one MHSU.

Letters were forwarded to the other 12 families members but only two responded. One family member came with the MHSU to the hospital and the interviews were conducted. The second family member called the social worker and explained that his brother was in jail; however, he made himself available for an interview with the social worker.

Two of the MHSUs refused to participate in the interviews indicating that they did not want to come back to Ekuhlengeni Care Centre. Despite careful explanations regarding the purpose of the interview, and an assurance that re-admission to hospital was not the aim, the MHSUs remained unconvinced and refused to participate.

Finally, ten interviews were held. Four were with MHSUs and six were with family members.

The fact that there were no contact details for one person, and that it was extremely difficult to locate people, points to the gaps that exist in terms of the discharge procedures at Ekuhlengeni Care Centre as well as the poor follow – up and after care services received by discharged MHSUs. This is a reflection of mental health services in the South African context, which is characterized by fragmentation.

DATA COLLECTION METHODS

Data was collected by means of unstructured face-to-face interviews. According to Bailey (1997:p96), *"Interviews conducted face to face are more intimate, allowing the interviewer to interact directly and develop rapport with the interviewee"*. With regards to the two Zulu speaking service users, an interpreter was used. The researcher was the only data collection "instrument". The researcher's experience and skills as a social worker, working with MHSUs for ten and half years was also used in the research process. In the time that the researcher spent working in this field, a lot of work was done in terms of counselling families and MHSUs, facilitating their re-integration into the community by means of, placements in community resources and their families. This experience led to the social worker undertaking this study and also determined the research questions in this study.

The participants were made to feel at ease, reassured and motivated to give honest answers. Face to face interviews also provided an opportunity for the interviewer to 'read' non-verbal cues of the interviewee. When non-verbal cues indicated confusion or lack of understanding, the question was rephrased (Bailey, 1997). This was very important because MHSUs and some family members who participated in the study did not understand questions posed to them, easily. This was also due to the insight and level of functioning of MHSUs. Therefore, there was a need for those questions to be phrased in very simple language.

Unstructured interviews provided detailed information from both service users and their families on their perspectives concerning their experiences since the service users' discharges.

The researcher was careful when using unstructured interviews not to get sidetracked and lose the original purpose of the study.

I used an interview guide with five broad questions around which to probe. These were:

Unstructured interview guidelines for interviews with MHSUs
1. What is a typical day for you like?
2. What sort of relationship do you share with your family?
3. How often do you attend the local clinic?
4. What services do you receive from the psychiatric clinic, hospital, etc?
5. How did you learn to cope with living at home again?
6. What positive events have happened to you since your discharge?
7. What are your recommendations with regards to preparing future MHSUs from Ekuhlengeni Care Centre for discharge into the community?
8. What have been some of the challenges that you have faced?

Unstructured interview guidelines for relatives of MHSUs
1. What is a typical day for your relative like?
2. How are the relationships he/she shares with you and the rest of the family?
3. How often does he/she attend the local clinic?
4. What services do you receive from the psychiatric clinic, hospital, etc?
5. How did you and the family learn to cope with living with your relative at home again?

6. What positive events have happened to you and your family since his/her discharge?

7. What changes have you noticed in MHSU since his/her discharge?

8. What are your recommendations with regards to preparing future MHSUs from Ekuhlengeni Care Centre for discharge into the community?

An audio tape recorder was used with the permission of the participants. The interviews were transcribed afterwards. The researcher obtained the participants' consent to use the audio tape. The researcher also wrote notes continuously.

METHODS OF DATA ANALYSIS

Data analysis was an ongoing process and data was analyzed according to a sequence of analytic procedures proposed by Miles and Huberman (1994).

The sequence was as follows:

1. The tape-recorded interviews were transcribed. After the tapes had been transcribed, they were shredded and the notes were kept in a locked drawer to ensure confidentiality and to protect the identity of the interviewees.

2. Codes were given to field notes drawn from interviews held with MHSUs and members of their families.

3. Reflections and other remarks were noted in the margins.

4. The data was sorted out in order to establish similar phases, patterns and themes. These patterns, commonalties and differences were noted in order to be considered in future interviews.

5. This gradually built on generalizations that were consistent in the database.

6. Once the data had been organized and described, the next step was to consider causes, consequences and relationships in the data (Bailey, 1997).

The researcher also considered the research questions that were formulated at the onset of the study and the interpretations made during data collection.

TRUSTWORTHINESS AND AUTHENTICITY OF THE RESEARCH

Qualitative research needs to comply with standards of trustworthiness and authenticity.

Trustworthiness

"Trustworthiness demonstrates elements necessary to ensure that there can be confidence in the research finding" (Rodwell, 1998:p96). These elements are credibility, dependability, confirmability, and transferability. The intention is that these elements will assist in assessing quality and will defend the methods, results and conclusions drawn (Green et al, 1988 cited in Rodwell, 1998).

Table 1: Steps ensuring trustworthiness of data

STANDARD	STRATEGIES
Credibility: how accurate are the findings?	Persistent observation
	Peer debriefing, for example, discussions with colleagues
Dependability: were the procedures used to gather, analyse and interpret data within accepted constructionist practice?	Records of data collected as well as records of data analysed
Confirmability: how reasonable is the logic and is the theory developed	Records of data collected as well as analysed with interpretations and

derived from the data?	conclusions in the final report.
Transferability: can the lessons learned and knowledge constructed in one context have usefullness in another context.	Use of "thick descriptions"

Authenticity

Authenticity reflects an interest in the quality of the process of the research carried out. The researcher ensured that fairness was maintained by representing all viewpoints. The researcher also ensured that the different perspectives used were considered for merit and worth. With regards to ontological authenticity, the researcher became familiar with the socio-political, economic and cultural contexts related to the mentally ill persons.

ETHICAL CONSIDERATIONS

"The scientific community has responsibilities not only to the ideals of the pursuit of objective truth and the search for knowledge, but also to the subjects of their research....the researcher has always to take account of the effects of his (sic) actions upon.....subjects and act in such a way as to preserve their rights and integrity as human beings. Such behaviour is ethical research" (Bulmer, 1982 cited in Humphries and Martin, 2000: p70).

The University of Kwa-Zulu Natal granted ethical approval for this study and the following ethical considerations were taken into account.

1. The researcher has ensured that the findings have been reported honestly and no fabrications were made or data changed, and that the research contributes to already existing knowledge.

2. Due to the vulnerability of the subjects who were used in the study that is mental health service users, the researcher was especially careful not to take advantage of them. To avoid this, their caregivers i.e. their families were included in the consent process.

3. The researcher abided by the research design as presented to the ethics committee. There was no need to redesign the study.

4. The researcher has reported all findings of the research even though the findings might not support the assumptions made by the researcher. The limits of the findings as well as the constraints regarding the methodology used have also been reported.

5. The participants were informed that their participation in the research was voluntary and no harm would come to them should they participate. This was further entrenched in the informed consent forms. Two people who were approached to participate in the study refused and I respected this refusal.

6. The researcher also ensured that the identity of the participants remained confidential by removing all the identifying information as soon as it was no longer required.

7. The participants were informed of the researcher's identity as a social worker at Ekuhlengeni Care Centre as well as a Masters in social science degree student. The participants were informed that the purpose of the study was for the completion of the Masters degree.

8. The researcher has recognized and acknowledged all participants in the research. All sources used for the research have been acknowledged whether consulted directly or indirectly.

9. The researcher was also bound by the ethics of her professional body in carrying out this research (Babbie & Mouton, 2001)

LIMITATIONS OF THE STUDY

Interviewing MHSUs who had varying degrees of mental illness was very challenging. Some were able to engage in the discussion in a meaningful manner while others found it difficult to do so. The depth of the information gathered was thus not always consistent. However, a concerted effort was made to structure the questions as simply as possible. The researcher is a qualified and experienced social worker in the field of mental health.

The use of an interpreter was also a limitation because the researcher felt that meaning may have been lost in the process of translation. This was despite using the services of a person who understood the importance of the research and the need to translate exactly what is being said in the interview.

Although this was a qualitative study and there was no intention to generalize the results obtained, the small sample is of concern. We do not know whether those who could not be traced were functioning well, in which case the results of this study would be limited. Despite this limitation, I believe that the study has relevance and as will be seen in the following chapter which points to a number of concerns in the care of mental health service users and their families.

CONCLUSION

This chapter centered on the methodology. Attention was paid to the following: the research paradigm, the research design, the sampling strategy, data collection and analysis as well as the ethical considerations and limitations of the study. In the following chapter, the researcher will focus on the analysis of the data collected.

CHAPTER FIVE
LIFE AFTER DISCHARGE FROM EKUHLENGENI CARE CENTRE:
ANALYSIS AND DISCUSSION OF RESULTS

INTRODUCTION

Mental health policy in South Africa emphasizes community care. In essence, this refers to and relies very heavily on placement with family. The mental health system has the hospitals, on one hand providing institutional care, and the family providing care in the community, with very little in between. There has not been a noticeable improvement in the quantity of residential facilities in the community for mental health service users. This challenge is encountered by social workers in the mental health field on a daily basis as the facilitation of placements into the community is an integral function of this professional group.

This chapter will present the main findings from the study. The findings are analysed within the context of the eco –systems theory which sees people as part of a complex system of relationships involving levels of environment (Bronfrenbenner, 1979 cited in Berk, 2001).

The chapter begins by describing the participants and then goes on to present the findings under the following headings: Individual functioning, impact on family and community support systems. The chapter ends with a discussion of recommendations made by the participants.

INTRODUCING THE PARTICIPANTS

Six family members were interviewed in this research as well as four MHSUs. Of the four mental health service users, Mr. Jabulani and Mrs. Jessica (names have been changed to maintain confidentiality) refused to participate in the interview as was discussed in the chapter on methodology.

Table 2: Summary of research participants

	Family member	MHSU
Family 1	Mrs Thandi*	Mr Jabulani
Family 2	Mrs Zama *	Mr Ayanda*
Family 3	Mrs Grace*	Mrs Jessica
Family 4	Mr Sipho*	Mr Danny
Family 5	Mrs Reshma*	Mr Kevin*
Family 6	Mrs Jayshree*	Mr Allen

* denotes the research participants

The details of each of the families is as follows: (names have been changed to protect the privacy of research participants)

Family 1: Mrs. Thandi had her uncle, Mr. Jabulani, discharged into her care after he was admitted at Ekuhlengeni Care Centre for 2yrs and 8 months. He had a diagnosis of schizophrenia. They lived in KwaMakhutha, a predominantly black community south of Durban. Mr Jabulani had frequent relapses due to him not being on any treatment after his discharge. Efforts by his family to obtain assistance from the South African Police services proved unsuccessful until two months prior to the interview with the researcher.

Family 2: Mrs Zama and her son, Mr Ayanda also live in KwaMakutha. Mr Ayanda was diagnosed with schizophrenia and had been at Ekuhlengeni Care Centre for 14 years. According to Mrs Zama who is approximately 80 years old, Mr. Ayanda experienced two relapses in the last year. He was readmitted to Town hill hospital on both occasions.

Family 3: Mrs Grace had taken care of her sister-in-law, Mrs Jessica. Mrs Jessica was discharged after being at Ekuhlengeni Care Centre for 2yrs and 4 months. She was discharged into the care of her maternal cousin but after a few months she went to live with Mrs Grace. She then ran away from Mrs Grace to

live with her aunt for a short while until she was admitted to the Aryan Benevolent Home (ABH) where she resides to date. Mrs Jessica had been diagnosed with Schizophrenia. Since her discharge from Ekuhlengeni Care Centre, Mrs Jessica had experienced relapses, however, she was not readmitted to any hospital. This could be attributed to the fact that ABH has a visiting doctor as well as a relationship with the regional hospital in the area and the Primary Health Clinic.

Family 4: Mr Sipho had discharged his brother, Mr Danny after seven years of him being institutionalized at Ekuhlengeni Care Centre. Even though Mr Sipho had discharged the mental health service user, he had taken him to live with his parents at Eshowe, in a rural area where the vast majority of residents are black. Mr Danny had been diagnosed with schizophrenia. At the time that Mr Sipho was interviewed he informed the researcher that Mr Danny was in jail. His parents had him arrested because he had become very violent and destructive at home. He indicated that his parents were unable to cope with the mental health service user because of his difficult behaviour. Both parents were of a pensionable age.

Family 5: Mrs Reshma lived with her brother, Mr Kevin who was discharged from Ekuhlengeni Care Centre after being admitted for 2yrs and 2 months. Mr Kevin was discharged by his brother and taken to live with his parents. His dad passed away a few months after his discharge. The MHSU said, *"When I was released my father could not take it that I am here and that I am in the open."* Both his parents were aged. His mum passed away on May 2004. He continued to reside at home with his sister Mrs Reshma. Mr Kevin had been diagnosed with Schizophrenia and substance abuse. Mr Kevin had experienced relapses since his discharge and had to be readmitted twice for treatment.

Family 6: Mrs Jayshree, a woman aged 77yrs lived with her brother-in-law Mr Allen after he was discharged from Ekuhlengeni Care Centre. Mr Allen was admitted to the hospital for 2yrs and 5 months. He was diagnosed with organic

brain syndrome. According to Mrs Jayshree he had passed away 2 and half years ago. He never recovered after being hit by a car. From the information obtained from Mrs Jayshree, Mr Allen had not relapsed after his discharge and he was never readmitted.

INDIVIDUAL FUNCTIONING

In this section, the individual functioning is described in terms of self care, social behaviour, communication, and ability to sustain relationships, performance in work activities as well as medication compliance.

On discharge

All six family members interviewed indicated that their relative was well when they were initially discharged from Ekuhlengeni Care Centre. There were positive changes in all the mental health service users since their initial admission to the centre. This is reflected in a statement by Mrs Grace who said, "*Yes there were a lot of changes in her. You know when she came out of Ekuhlengeni Care Center she was like you and me.*"

The family members were optimistic about the discharge of mental health service users when they were initially discharged in light of their good behaviour and the general manner in which they carried themselves out. This was very evident when the faces of some family members lit up when they spoke of the mental health service users when they were discharged.

These revelations by mental health service user's relatives indicate that their placement at Ekuhlengeni Care Centre was beneficial to the MHSUsof an obvious benefit to them specifically in terms of the treatment and rehabilitation programmes that they were exposed to as they had attained improved functional status. Clearly, the provisions of the Mental Health Care Act 17 of 2002 that " *every mental heath care user must be provided with care treatment and*

rehabilitation services that improve the mental capacity of the user to develop to full potential to facilitate his/her integration into community life" had been met.

Deterioration in condition after discharge

Unfortunately, the good progress made by MHSUs was not sustained after discharge. This finding is not unique to this study as similar findings were reported by a study conducted by Shankar and Muthuswamy (2007). Many of the caregivers who were interviewed felt that the progress made by their relatives as well as the activities they were occupied with did not continue when they were discharged.

In this study, five of the family members indicated that after a matter of a few months their relatives started to present with behaviour problems such as refusal to do any chores at home, lack of personal hygiene, aggression, running away from home, inappropriate sexual behaviour, defaulting treatment as well as substance abuse.

Only one family member, Mrs Jayshree indicated that her relative continued to function well. However, this comment must be seen in the light of the fact that Mr Allen had passed away and it may be that Mrs Jayshree did not want to blemish the name of her deceased son. Mrs Jayshree did allude to some problems when she said, *"No, no problems at all, only problems were that liquor. He couldn't get out of it."* A further hint that the information provided by Mrs Jayshree was not entirely accurate is the fact that Mr Allen passed away a few months after being knocked by car while crossing the road. However, according to Mrs Jayshree, Mr Allen only stayed at home and never went anywhere.

Social behaviour

Leaving the hospital had presented some problems to the MHSUs who were interviewed. According to Mr Ayanda, the challenge he faced was accepting that it is dangerous to be out late at night. He said, *"one day when I was walking*

around I saw a lot of blood. In my home area they cut a person's ear and little finger. It was a challenge to me because I learned that I do not need to be outside at night, to walk around at night."

Mr Kevin indicated that his challenge was with regards to socializing and being aware of how he talks to people. He went on to explain that he got involved in his brother's marital problems when he found out that his brother was divorcing his wife for another women. This resulted in arguments which, lead to him assaulting his brother. He indicated that he was angry that his brother was leaving his wife and children and this had led to his violent outburst. However, this was construed as a relapse and he was placed on treatment again.

Four of the five mental health service users who had relapsed displayed aggression by being destructive at home by breaking windows and other items in the house. Mr Kevin and Mr Jabulani became violent and physically assaulted their family members. According to Mrs Reshma, when referring to an incident with mental health service user and his deceased mother, she said, *"He wanted to push her from the top of the stairs. Sometimes he will chase her out at night, she will be sitting outside......until his music go off and everything is quiet, she will open slowly and come inside. When he used to put the music on at night he used to put it off at 9pm or10pm."*

Due to the aggressive behaviour of this mental health service user, his mum actually had his medication reduced because he insisted. This is an indication of the fear and abuse experienced by family members who will do anything to keep the peace in the light of aggressive behaviour on the part of their relative. As far back as 1965, Waters and Northover conducted a study that reported similar findings in which, *"many schizophrenic men occasioned moderate to severe hardship to their relatives in terms of social embarrassment, inconvenience, and behaviour which frightened them or caused tension in the family"* (cited in Kuipers, 1992: p293).

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It also appeared as if some mental health service users use their aggressive behaviour to manipulate their family members with the incorrect knowledge that they are "protected" by being diagnosed as a psychiatric patient. In an interview with Mr Kevin, he was almost jubilant that nobody could assault him as they will be arrested because he is a "state patient" and if he assaults anyone he will be safe because he is a psychiatric patient. This statement by him that *"The thing is the cops couldn't arrest me, she was bleeding but they couldn't arrest me because I am a psychiatric patient. "*and *"I am a state mental health service user you don't lay your hands on me if I did something wrong,"* reflects this.

Poor attention to personal hygiene was also a problem presented by Mrs Jessica and Mr Jabulani. They showed no interest in their personal appearance when they relapsed and they refused to bath or change their clothes. Mrs Jessica also danced and sang on the road and looked in the bins. She also had a tendency to run away for home after two to three months. According to her family member, Mrs Grace, Mrs Jessica used to also be incontinent when she was very ill.

Problems with inappropriate sexual behaviour were also noted. Mrs Jessica and Mr Kevin displayed inappropriate sexual behaviour. Mrs Jessica used to be promiscuous and lift her dress on the road whilst Mr Kevin, according to his family member, Mrs Reshma, *"rubbed his privates on the wall."* The problems presented by the mental health service users in this study are not unique and similar findings were illustrated in studies conducted by prominent writers in mental health many years ago. Grad and Sainsbury's (1963a, b cited in Thornicroft, Brewin, Wing, 1992) found that severe burden was related to problems of aggression, delusions, hallucinations, confusion, and poor self-care. Hoenig and Hamilton (1966; 1969) cited in Thornicroft, Brewin and Wing (1992) supported these findings when they confirmed that relatives more often reported aggressive behaviour, extreme seclusion and withdrawal as being problematic. Some studies presented findings that negative symptoms of social withdrawal,

lack of conversation, underactivity, slowness and having few hobbies were most problematic (Creer & Wing, 1974 cited in Thornicroft, Brewin, Wing, 1992) whilst further studies conducted found that disruptive behaviour caused much suffering to relatives. Offensive behaviour, rudeness and violence were established to be upsetting to carers if they had to deal with them (Gibbons et al, 1984 cited in Thornicroft, Brewin, Wing, 1992).

In this study, the behaviours presented were probably due to mental health service users' poor compliance to their medication together with the stresses of living in the community and the lack of support they received from the community.

Medication compliance

The deterioration in the functioning of MHSUs when discharged from hospital may be explained, in part, by their poor medication compliance. It was revealed by all six family members that their relatives had difficulties in taking their medication regularly.

Mrs Grace said that there were times when Mrs. Jessica would not take her medication, especially on the days that Mrs Grace went to work. She indicated that when she didn't take her medication she *"tends to go off"*. She was promiscuous, used to also lift her dress and dance on the road, and also search the bins kept at the butchery. This was of particular concern as the people at the butchery informed Mrs Grace that they will not take any responsibility for her should anything happen to her because they place chemicals in the bins. Mrs Reshma also mentioned that her brother Mr Kevin always had a problem taking his medication. He constantly swore at his mother for her to reduce his medication, which she did, against her better judgement as she was intimidated by Mr Kevin, she said, *"That was in March/April and in May 2004 she passed away. From July you could see things were not right, he was talking a whole lot of nonsense i.e. he ran a show in Stanmore. Then one day my brother was here he was talking and he was not making any sense, then my brother took him to*

the clinic put him back on his normal dose. He doesn't want to be on the injection."

The reasons for poor compliance to medication are varied. A very renowned writer in mental health field, Lamb (1993), stated that mental health service users fail to take their psychotropic drugs due to worrying side effects, fear of tardive dyskinesia (involuntary movement which generally affects the tongue but can include other parts of the body. This happens after a long period of dopamine blockage), denial of illness and in certain cases medication is not taken to prevent the depression and anxiety which results when they see their reality too clearly. They are also inclined to find the grandiosity and a blurring of reality more easier to cope with than a relative normality induced by drugs (Van Putten et al, 1976 cited in Lamb, 1993). A study conducted by Carpenter et al (2002) also ascertained that MHSU felt that they were not sufficiently educated about their prescribed medication, how it works, possible side effects and alternatives. The provision of such information is particularly significant because the onset of side effects is one of the reasons why MHSUs default treatment and this increases the risk of relapse (Robinson, 1999 cited in Carpenter et al, 2002).

The above was further reinforced by Wright (2000) who indicated that despite the accessibility of extremely effective drugs, medication compliance is still a major problem that is experienced in clinical practice. In a study conducted by Olfson, Mechanic, Hansell, Boyer, Walkup and Weiden, (2000, cited in Wright, 2000), they compared the characteristics of MHSUs who were regarded as being non-compliant by stopping their medication for one week or more within the first three months after discharge. About one-fifth of the 213 MHSU met the criteria for non-compliance. These MHSUs tended to abuse substances more, their insight into the awareness of their illness was less, and their family had also refused involvement with their care during hospitalisation. Therefore any efforts to resolve non-compliance should ensure that in addition to interventions to develop patients' insight and their general care after discharge from hospital,

health professionals should engage with MHSUs and also take account of their immediate social environment.

In a study to understand the experiences of people with serious mental illness, Lester and Tritter (2005) found that mentally ill persons viewed both their illness as well as psychotropic medication as imposing restrictions on their ability to live their lives and found it oppressive. Side effects were often difficult to live with and this was compounded by the lack of discussion and information received from health professionals. The MHSUs relayed experiences of not being believed when they complained of the side effects and the influence on the quality of their lives. They also indicated that requests for doses to be reduced resulted in them being increased, or new tablets were prescribed to counter act the side effects that was experienced.

Karp (2001: p59) wrote *"Because of the stigma attached to the mental illness label, the debilitating side effects of powerful psychotropic medications, and often the inability of mentally ill people to appreciate how strange their behaviours seem to others, many ill family members simply deny that they are sick and, thus, refuse any form of treatment. In those families where an ill person does not comply with medical treatment, the reservoir of care giving sympathy quickly evaporates........Whether or not their ill spouse, child, parent, or sibling undergoes therapeutic treatments, everyone interviewed agreed that they must bear significant responsibility for getting well. Exhibiting such responsibility becomes, at a certain point, the sine qua non of their willingness to continue as care givers."* This comment is very important because MHSUs need to understand that they are ultimately responsible for their own health just like any other person suffering from a physical chronic condition.

In this study the researcher is of the opinion that mental health service users' non-compliance is indicative of their mental state, their lack of insight into as well as their understanding of their psychiatric conditions. This could also be due to

their inability to accept that they have a mental illness, which can also be attributed to the stigma that is generally displayed towards mentally ill individuals. One can deduce from this that the structured, routine and supervised set-up of Ekuhlengeni Care Centre was very beneficial to the mental health service users and that they were unable to comply with treatment when they were discharged because they lacked the structure and supervision. Either they were not sufficiently educated on the importance of complying with their treatment or their mental condition is such that they are unable to appreciate the value of ensuring that they take their medication diligently. A further factor may relate to the lack of regular follow up and support form the mental health professionals.

The emergence of Multi-drug resistant (MDR) and Extreme-drug resistant (XDR) tuberculosis (TB) attests to difficulties in ensuring compliance.

It was also evident that family members themselves were not in tune with the importance of their relatives taking their treatment regularly. According to Mrs Thandi, her uncle has not been on medication since his discharge from Ekuhlengeni Care Centre that is since the completion of his month's supply of treatment, received from the centre on discharge. He refused to go for treatment and due to his aggressive behaviour, they were afraid of him. At the time of the interview with the researcher, he was still not on treatment. He was unkempt and he answered questions posed to him irrelevantly. He was also very difficult in that he refused to co-operate with the interviewer. It can be concluded that Mrs. Thandi was not aware that the mental health service user taking his treatment regularly was tantamount to ensuring that he remains stable. This indicates that relatives are not being educated about the importance of medication compliance and as a result did not supervise mental health service users in terms of their treatment. Compliance to medication need not be a problem and structures can be put in place to ensure that people are provided with adequate support to take their medication. For example, Leff (1997) ascertained, when he followed up on long-term mental health service users who were discharged from hospital to

community centers, that mental health service users who had presented with problems complying with medication decreased from 87 per cent to 78 per cent over one year and a further decline was observed to 68 per cent by the fifth year. He indicated that this could be attributed in part to a programme run by the pharmacy department within the hospital that taught as many patients as possible to be responsible for taking their oral medication prior to their discharge.

IMPACT ON FAMILY

Family life is important for MHSU as much as it is necessary for persons who are mentally healthy. It was written by Rapp (1998:p26) that "The quality of a person's life, their accomplishments, and the outcomes of their life are shaped by the qualities of niches within which a person live". A niche is "the environmental habitat of a person or category of persons" (Taylor, 1997 cited in Rapp, 1998:p26). The kind of social relations that people enjoy influences their environment. Social relations benefit people in terms of the companionship they enjoy, the emotional support they receive as well as caring, partnership, sexual relationships, recreation, socialization and the opportunities to give in these relationships (Rapp, 1998).

However, it was clear from the interviews that the discharge of MHSUs had a dramatic impact on family life and that family life was not always easy for these MHSUs and their relatives with regards to social relations.

Family relationships

Aggressive and anti-social behaviour on the part of MHSUs impacted negatively on family relationships as reported by Mr Ayanda, Mr Kevin and Mr Sipho whose brother, Mr Danny, was jailed by his parents. For example, Mrs Reshma reported that Mr Kevin socializes and communicates with his family on very rare occasions; most of his time at home is spent in isolation behind closed doors.

"When he is at home he is always inside his room. He is practically the whole time inside his room. He has his music on and when he switches it off we don't know whether he is sleeping or maybe he is by the window, but he is in his room with the room door closed," she said.

The problems experienced by families of mentally ill persons with regards to relationships are nothing new. Studies conducted by Wing *et al* in 1964 which tracked 113 schizophrenic mental health service users for a year after discharge revealed that in cases where users returned to reside with their families, in nearly two thirds of these cases the social relations were strained (Thornicroft, Brewin, Wing, 1992).

An indication of the aggression experienced by relatives as well as the poor family relationships that prevailed is reflected in a statement by Mr Kevin when he referred to an incident with his sister, *"We had an argument and I hit her. One morning she got on my nerves, she pulled me aside, you know I am her brother she shouldn't lay her hands on me. I am a psychiatric patient; I am a state patient you don't lay your hands on me if I did something wrong. She pulled my face and punched me. I just gave her a hit, I punched her mouth."*

In some cases, MSHUs were able to behave appropriately with outsiders but treated their family badly. For example, Mrs Zama stated, *"He (Mr Ayanda) behaves well to people from outside not to family members."* She also explained that when she goes to talk to him he refuses to talk to her and he chases her away. She indicated that she feels very bad when this happens. According to Thornicroft, Brewin and Wing (1992) since MHSUs started to return to live in the community in the 1950s many studies have been undertaken to determine the effect this has had on the family. However, the fact of the matter is that much of what was recognized and documented then was still being documented in the 1990s (and indeed, as the results of this study, in the 2000s). This indicates that the professionals working with mentally ill persons have a problem accepting that

relatives might have needs, which therefore impacts on service provision. However, opportunities for working with relatives have developed and *"relatives are now being seen as a resource rather than a nuisance, and they are being offered support and help"* (Kuipers and Bebbington, 1985, 1990; Mintz et al, 1987 cited in Thornicroft, Brewin and Wing, 1992:p292).

It would also appear from the data that family members do not always understand the nature of the mental health service user's illness. Mr Sipho was of the opinion that his parents do not understand his brother's illness and this contributed to the poor relationship they shared. This is indicative of the insufficient information imparted to families to ensure that they understand the MHSU in the context of their illness. Due to this lack of understanding, family members have unrealistic expectations of their mentally ill relative and this result in conflict. Depending on the nature of the conflicts that arise it is very often regarded as a sign of relapse and deterioration in the condition of mentally ill persons.

Lamb (1982, 1993) wrote that when trying to make one's way in the world, one battles to attain some independence, to select and succeed at a vocation as well as to form satisfying personal relationships and to achieve a sense of identity. Without the ability to cope with stress the efforts made by mentally ill persons frequently lead to failure which is accompanied by feelings of hopelessness. A person who is inclined to retreat into psychosis experiences acute psychotic episodes and subsequent repeated admissions in their efforts to achieve in life. The situation is exacerbated when these persons are in an environment where unrealistic expectations originate not only from themselves but also from relatives and mental health professionals (Lamb, 1993). This therefore displays the strong link between the lack of understanding of MHSU's illness and the unrealistic expectations of family members who as a result of their lack of information, is unable to understand the limitations placed on mentally ill persons and their ability to achieve and function like mentally healthy people.

For others the time of relapse was a time of difficulty and it was then that family relationships were strained. Mrs Jessica and Mr Jabulani shared a poor relationship with their relatives when they relapsed, otherwise they got on well with their relatives. This again stresses the importance for family members and everyone around mentally ill persons to have an understanding of mental illness. The late mental health service user, Mr Allen was reported by his family member to have got on well with his family all the time but as discussed previously, this information must be evaluated in the light of the fact that he has passed on.

Contribution to home environment

According to Sayce (2000), there was only one study by Greenberg et al (1994), wherein it was ascertained that where they resided together 50%-80% of family members and friends said mental health service users contributed to the home by doing household chores, shopping, providing emotional support, lending a listening ear to problems, providing friendship and also offering news related to family and friends. However, this was not the case in this study.

All six family members in this study indicated that since their relative was discharged, there was no positive change in the family. This means that the mental health service user added no value to their families' lives. In fact, it would appear according to the information provided by five of the six family members interviewed that mental health service users, rather than making positive contributions to the lives of their family members, actually contributed negatively by being destructive, aggressive, and violent. They were amotivated and presented with odd behaviour that community members informed family of. They brought about disharmony to the lives of their relatives and compounded problems that relatives were already experiencing. This is reflected in a statement by Mrs Grace, *"I cannot keep running around with her because I have my own set of problems to see to."* By being destructive the mental health service user contributed to the financial burden of their families. Mrs Zama

indicated *"He was breaking windows, even before he used to break all the windows, as I am talking right now we don't have the windows, we don't even have electricity because they disconnected it."* The family member's frustration and hopelessness of her situation was evident when she was relaying the above to the researcher.

Dependence on family

Both Mr Ayanda and Mr Kevin are independent in terms of activities of daily living. Mr Kevin leads a very independent life. According to his sister he collects his grant, pays his portion of the lights and water, pays his insurance, buys his groceries, and does his own cooking, washing and ironing. Mrs Grace also mentioned that it was important for Mrs Jessica to *"be responsible. She needs to know how to handle money, she needs to handle her own shopping, and she needs to know how to wash her own clothes."*

However, most of the family members interviewed indicated that MHSUs don't do anything for themselves, even maintaining their general hygiene is not taken for granted and they often neglect their appearance and have to be reminded to bath. One MHSU was in receipt of a grant but this did not positively impact on the family as he used the money for cigarettes, and personal requirements.

Similar problems were recorded by Trieman (1997), a member of the team for the assessment of psychiatric services (TAPS) that researched the transition to the community of mental health service users discharged from Friern and Claybury hospitals in London. The problems presented by ex-long-stay mental health service users that were discharged to residential homes were usually *"poor hygiene, lack of motivation and poor social skills"* (Trieman, 1997:p64). Behaviours such as aggression, substance abuse or arson were not tolerated in majority of the residential homes and were also used as criteria for excluding such residents for acceptance.

However, Mr Ayanda indicated that the best thing about him being discharged is that he is free and can walk around and live his life. Mr Kevin indicated that for him the positive experience he has had is the good relationships he shares with his two nephews and his sister understands him better. This is in keeping with the findings of Leff (1997), where he found that after mental health service users were discharged from long-term hospital care into community homes, they had gained more friends, improved their domestic skills and enjoyed their freedom in the community.

Burden of care

"As little as we know of illness, we know even less of care. As much as the ill person's experience is denied, the caregivers experience is denied more completely (Arthur Frank, cited in Karp, 2001: p3).

As far back as 1985, Platt defined burden as *"the presence of problems, difficulties or adverse events which affect the life (lives) of the psychiatric patients' significant others (e.g. members of the household and/or the family)"* (Platt, 1985 cited in Kuipers, 1992:p292). Other definitions of burden were also made, approximately forty years ago that still holds true four decades later i.e. *"the impact of living with a (psychiatric) patient on the way of life, or health of family members"* (Brown, 1967 cited in Kuipers, 1992:p293); *"the difficulties felt by the family of the psychiatric patient"* (Pai & Kapur, 1981 cited in Kuipers, 1992:p293).

The burden of care of a mentally ill relative was evident in all the interviews that were carried out. However, this was more so with Mr Ayanda and Mr Kevin. They appeared to be frustrated that mental health service users are their responsibility and they receive no assistance from the rest of the family. Mrs. Reshma indicated *"I keep asking the question what is going to happen to him when I move out. My intention is to move out because I feel my family is being unfair to me. Because I didn't have a place to stay I am staying here. Nobody*

thinks to relieve me by taking mental health service user over the weekends, to give me a break."

Four of the mental health service users were discharged into the care of their aging parents or relatives. In view of the life tasks of elderly people (e.g. Erikson), one has to question the fairness of this. It is at this point in their lives that they do not have the strength to deal with their mentally ill relative and are very vulnerable when their relative becomes aggressive and violent.

Lazarus (2005:p66) indicated that available community resources might be essential in decreasing the burden associated with caring for people with chronic mental disorders. These resources include *"day care, workshops, or drop-in centers."*
She explained further that without these resources placements of mental health service users with their relatives will not be sustainable because their family will not hang on to their employment, daily activities and the mental health service user will not be occupied or supervised adequately. However, participants in this study did not have the benefit of these resources because they do not exist in any great number in SA.

In keeping with this, findings reported in a study conducted by Shankar and Muthuswamy (2007) ascertained that many of the caregivers that were interviewed felt that the progress made by their relatives as well as the activities they were occupied with did not continue when they were discharged. It was also believed that due to there being no follow-up care, motivating their relatives to become involved in activities fell on them.

According to Shankar and Muthuswamy (2007) due to the lack of funding for community services, family caregivers especially, women are forced to take on the responsibility of caring for relatives who are mentally ill. This is very true when one looks at this particular research where five of the six family members

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interviewed are women caregivers. Karp (2001) explained that because women have traditionally taken responsibility for majority of the care giving tasks in families, this has resulted in caring becoming culturally undervalued just like women's domestic labour, which is accorded very little respect. This is further illustrated in that traditionally female and caring professions are found to be at the lower ends of the professional prestige hierarchy. History has seen to it that care giving has been transferred to the personal area of the family, and it is regarded as the natural, moral duty of women to achieve.

There is also research that details the stress that is experienced by relatives who take care of family members who are mentally ill. This recognition of the stress endured by caregivers has resulted in governments and mental health service providers in many countries contributing to education and support programmes that are geared to assist caregivers not only to deal with the stress but also to tackle the problematic behaviour arising from mental illness. These programmes have also been suggested in studies conducted to promote saving on hospital care, decrease the rate hospitalisation and also reduce the need for crisis support (Dixon & Lehman, 1995; Solomon, 1996 cited in Shankar & Muthuswamy, 2007).

According to Shankar & Muthuswamy (2007) a huge amount of stress faced by caregivers can be linked to the provision of insufficient critical supports such as crisis information and support services, continuity of care, psychosocial rehabilitation programs to assist in skill development and involvement in work or education as well as caregiver counselling and respite services. There also seems to be no holistic approach to meeting the needs of caregivers. The findings emphasise that an important source of frustration for caregivers may very possibly originate from professional attitudes that convey feelings of guilt and self blame, lack of interest on the part of professionals towards the caregivers' practical knowledge of the illness, as well as caregivers being left out from decisions related to the treatment and care of their relative.

Relatives have needs to maintain their own mental health as well as quality of life to ensure that they pro vide an adequate, stimulating and not over stressful environment for their mentally ill relative. Because their needs are intrinsic to their roles as caregivers it is important that as mental health professionals we start providing services that are geared to these needs (Thornicroft, Brewin, Wing, 1992).

It is imperative that it is realized that the fates of societies and families are intertwined similarly to 'globalization' and its promotion of the premise that we live in a small and organically interconnected world. A national policy must be formulated with the goal of saving families in difficulties rather than standing by and doing nothing as they disintegrate. Societies must ensure that families are cared for and nourished in order that parents, spouses, children, and siblings can extend compassionate care to each other during moments of vulnerability, crisis, and illness (Karp, 2001).

COMMUNITY SUPPORT SYSTEMS

Much of the burden of care on families could be ameliorated by good community support systems. As long ago as the 1960s and 1970s mental health service users confronted difficulties such as the lack of necessary support and services necessary for the adjustment to living in the community. Needs such as a home, income, accessible health and mental health care, skills to cope with living in the community, support during crises, friends and meaningful employment were all too frequently unmet. Outpatient clinic services that were offered had very little impact on these critical areas (Hughes, Lehman, Arthur, 1996).

The importance of community support systems is reflected by one of the early pioneers in the field of psychosocial rehabilitation Irving Rutman when he defined psychosocial rehabilitation as *"a spectrum of programs for persons with long term*

mental illness. The programs are designed to strengthen an individual's abilities and skills necessary to meet their needs.......The goal of psychiatric rehabilitation is to improve the quality of life of psychiatrically disabled individuals by assisting them to assume as much responsibility over their lives and to function as actively and independently in society as possible" (Rutman, 1989 cited in Huges, Lehman, Arthur, 1996:p287). Rutman elaborated further that services are comprehensive and range from socialisation to individualized planning and case management, depending on the individual services that are offered on a short or long-term basis. Very importantly, it seeks to promote MHSUs ownership in rehabilitation. Unfortunately, the participants in this study experienced many problems in terms of lack of community support (Rutman, 1989 cited in Huges, Lehman, Arthur, 1996).

Challenges in respect of work and vocational activities

It is widely accepted amongst mental health care professionals that the participation of mentally ill persons in vocational activities is of paramount importance for their re-integration into the community. However, according to Leff and Trieman (1997) it is important to be practical about the job prospects of chronically ill mental health service user, taking into account the national unemployment rate. They indicated that it has to be questioned if it is fair to be expecting mental health service users over 60 years of age to take on work-like activities when it is accepted that majority of the healthy population retire at this age. For mental health service users who had been hospitalized for a long time the chances of working on the open labour market are slim, given the problem of explaining the long interruptions in their work record and the competitive nature of interviews. Five of the six family members indicated that their relatives were not meaningfully occupied during the day. Two family members indicated that their relatives refused to do anything; even simple tasks at home. The other two indicated that their relatives did assist in doing some chores at home. Mrs Jayshree indicated that she did not allow her relative to do anything at home. It appeared as though she felt that her relative should not be doing any chores

given his condition because she said in the interview *"He was just like a son to me and I used to look after him that was my duty to look after him."* It is quite clear that she was not educated on the importance of keeping mental health service user occupied at home as it will contribute to him functioning at an optimal level. Mrs Jayshree could have very well been influenced by her culture because traditionally it has been considered in the Indian community to be taboo for men to assist with chores in the home. Household chores were regarded to be the women's responsibility and as result men who assisted in the home with chores had their masculinity questioned and were looked on as not being 'man enough.' This was entrenched very much with Indian mothers and in this particular case Mrs Jayshree did not allow her relative to assist with chores at home because he was "like a son" to her. However, this perception is changing particularly amongst the younger generation where both partners are working and also in the way children, both male and female, are taught to be responsible at home by assisting with household chores.

Mrs Reshma indicated that her relative worked as a car guard for a doctor near their home. The doctor owned a building with other businesses, and his surgery was situated in the same complex. According to Mr Ayanda he did not help at home but he used to help outsiders to do gardening because he received tobacco or money to buy his tobacco. He obviously did not want to assist at home because he had no incentives. According to Mrs Zama, Mr Ayanda said he didn't want to help in the house because he had no energy. This could be attributed to his medication but also an excuse as he was able to help neighbours clean their gardens because he is rewarded for it. Perhaps too, Mrs Zama lacks the skills and the confidence to motivate him to assist around the house.

It is interesting to note that according to the policy on psychosocial rehabilitation in Kwa-Zulu Natal, a skills development approach is being adopted. It understands the need for mental health service users to receive skills development in a number of areas such as self-care, communicating with others,

parenting, recreation participation, pre-vocational and community access. However, the facilities to provide these services are not well developed and the MHSU who were part of this study have not had the benefit of these services.

The health system
Role of medical personnel

Karp (2001) indicated that in his compilation of two books on mental illness he has been struck by the negative feelings that mental health service users and caregivers have regarding psychiatrists. In all his conversations with caregivers there were more negative than positive comments about psychiatrists. He heard a few stories about psychiatrists who were very good and who were looked at as saviours, however more often *"caregivers complain about doctors who were unwilling to listen to what they had to say, who radically decontextualized things in a way that defied common sense, who were prone to snap judgments that seemed odd and uninformed, who were callous in their comments and demeanor, and who were sometimes cavalier in blaming caregivers for the problem"* (Karp, 2001:p216)

The above is reflected in the experience of Mrs Reshma who, on the one occasion when she was assaulted by her relative was told by the police to go and speak to the psychiatrist. This is her account of what transpired:" *When I spoke to the psychiatrist, I wasted my time because the psychiatrist sat in a deep conversation with him and I don't know what they spoke about when he called for me. He knows my sister very well because he treated her, so he was talking about unnecessary...... oh, you look just like your sister, how is your sister doing? Why don't you go to Jo'burg and live with your sister? I don't need to go to Jo'burg; I came here with a problem. ...... He is supposed to be telling him things but he is telling me, oh, he must have been provoked for him to assault me."*

It is important for medical personnel to always consider both sides of the story when relationship problems surface between mentally ill persons and their family members. They should be careful of not being manipulated by mental health service users and also not to undermine family members especially in the presence of the MHSU. This could lead to a lot of distrust felt by family members towards medical personnel; they will also view this as a lack of support in terms of their needs.

Revolving door syndrome

'Revolving door syndrome' refers to a process of ongoing admission, discharges and readmission. Lazarus (2005) indicated that the most likely outcome of this is that mental health service users are neither adequately treated as in-patients nor integrated effectively into the community.

From the six family members that were interviewed, five of them indicated that their relatives had experienced relapses. In the cases of Mr Kevin and Mr Ayanda this was so severe that they had to be re-admitted to Town Hill hospital. The fifth mental health service user who was not interviewed was arrested by police and was in jail at the time that the researcher was conducting the interviews. Although relapses are quite common, it can be concluded that with all these service users, non-compliance to medication was a major contributory factor in terms of their relapses. Mrs Jessica at the time of the interviews was admitted to Aryan Benevolent Home in Chatsworth. She was not manageable at home.

Conclusions can be made that mental health service users were not educated about the signs and symptoms of relapse and how to prevent it. It will also be beneficial to them if they communicated better with their relatives and also enjoyed improved support.

One mental health service user, Mr Ayanda apparently abused dagga and in his case this was also a contributing factor in terms of his relapses. However, he denied it and indicated that he bought dagga for others and not for himself.

The tendency for mental health service users to be readmitted was illustrated in the follow up, after one year of patients who were discharged from Friern and Claybury. It was ascertained that of the 671 patients who were followed up on, 102 of these mental health service users had been readmitted at some time to a psychiatric ward (Leff, 1997:82).

The frequent relapses of mental health service users have negative cost implications on the hospitals and it is necessary for processes to be in place in the communities that will prevent this.

Requests for re-admission

Five of the family members interviewed either requested for the mental health service users to be re-admitted to Ekuhlengeni Care Centre or had approached the Community Mental health social worker for assistance with placing the mental health service user back at Ekuhlengeni Care Centre, only to be informed that that was not possible due to Mental health service users' level of functioning or that it was their responsibility to look after the patient. With the last statement one wonders if this is fair on family members. Government is looking at shifting the locus of care of mental health service user to that of families within the community, however is this a good thing for some families whose quality of lives really take a beating and they themselves end up being stressed by the problems experienced with mental health service users?

Support Systems

In relation to support received it was interesting to note that in this study five family members indicated that the only service they received was the treatment given to their relatives on a monthly basis from the primary health care clinic.

They received no visits from the community mental health social worker and there was also no psycho-social rehabilitation programme in place for them to be involved in the community. According to Mrs Jayshree when she had initially accompanied her relative to the clinic, the doctor used to query about what the patient is doing at home and on one occasion the mental health service user complained to the doctor that his relative don't buy alcohol and snuff for him. The doctor told him that he is not supposed to have alcohol because he is taking medication.

The above is testament to the fact that follow up services is limited to medication management and is complementary to the traditional custodial pattern of care offered in psychiatric hospitals.

There has always been an inadequate continuity of mental health care services in the community. In fact there has been a fragmentation of mental health services to such an extent that there is no link between hospital and community care resulting in many mental health service users getting lost in the system. A case in point is that of Mr Jabulani who has been on no medication for eight years. When mental health service users are discharged from the institution or hospital it is the families' responsibility to ensure that the mental health service user goes to the nearest primary health care clinic for treatment. If this does not happen there is no process or system in place to ensure that if the mental health service user is not taken to the clinic that he will be traced and followed up on. Many mental health service users get lost as a result of the fragmented system of mental health service delivery and they need to be found so that they can access the system in the first place (Zealberg et al, 1993 cited in Bachrach, 1997). According to Lazarus (2005), if there are no links between institutional and community care or if it is fragmented and if sufficient provision for mental health care within community health services is not facilitated in terms of adequate staffing, ensuring that there are no interruptions in the supply of medication or the ability to react to crisis, there will be an increased chance of relapses taking

place. Re-admissions of mental health service users may also be much more difficult. The difficulties experienced will result in an increased unwillingness by everyone to try community placement for mental health service users again.

It was clear from the interviews held that not all relatives shared a close relationship with their mentally ill relative and did not consider providing care their responsibility.

According to Karp (2001), some observers find the heartlessness that describes family relationships remarkable. However, to him the love, caring, and connection that holds family together is remarkable. It is important to note that the family like any other organization will break down if too much is expected from it. Systems theory teaches us that systems strive for homeostasis, and a balance of resources and demands is necessary to achieve this.   However when the demands exceed the resources this leads to disintegration. It is therefore imperative that the family receive the support they require at all times and are not left to deal with the mhsu on their own. Just as important is the need for the community mental health workers to closely monitor and supervise mental health service user compliance to treatment.   It is important that the South African government keep families intact by providing a sound integrated system of services to support the family in caring for their mentally ill relative.

As far back as 1959, writers such as McDougall pointed out *"some may say that to change the right to stay in a modern, adequately equipped hospital, for the right to share the kind of services which some local authorities provide under their health and welfare services is a doubtful privilege"* (McDougall, 1959 cited in Carrier and Kendall, 1997: p10). He further pointed out that community care could place an almost intolerable burden on family. Without adequate support from psychiatrists and social workers, it could become dangerous. *"Community care could very easily become 'community chaos' with retrogression in public*

attitudes which might bring back the old cry of 'lock them up' again" (McDougall, 1959:229 cited in Carrier and Kendall, 1997:p10).

Titmuss (cited in Carrier and Kendall, 1997) pointed out a concern in 1968 that unless the meaning community care was realistically examined, then wishful thinking was being indulged in. He indicated that a situation was arising where the emphasis from the institution was being shifted to the community. He explained that this was a trend, which was in principle being applauded whereby the care of the mentally ill was being transferred from *"trained staff to untrained or ill-equipped staff or no staff at all"* (Timuss, 1968 cited in Carrier and Kendall, 1997: p10). Twenty-nine years after this statement by Titmuss it is quite evident from the findings of this study that his statement and the situation that he had envisaged did actually happen. Mental health service users are being discharged to the care of their families and very little or no training is being done to cope with MHSUs.

According to Lamb and Bachrach (2001: p3) places where community care has been carefully planned and well funded also have mental health service users that do not do well. They indicated that part of the reason for this is that the services required by mental health service users have changed. *"For example, some "new" long-term severely mentally ill persons have found it extremely difficult to sustain themselves in the community. Among other problems, their easy access to alcohol and other chemical substances has greatly exacerbated their symptoms and has interfered with any progress they might have made, a fact that was largely overlooked in the early years of de-institutionalisation."*

It can be deduced that the impact of mental illness not only results in decreased quality of life, loss of ones independence as well as capacity to work and poorer social integration for the mental health care user but it also creates a burden of caring for the family and the community at large and it contributes to lowered economic production (Thornicroft and Tansella, 1999). Mental illness also

impacts negatively on health and welfare costs in terms of cost of treatment and the distribution of disability grants.

Societal attitudes - Experiences of stigma and prejudice

This aspect was not specifically explored in the interviews however from the interviews it can be deduced that stigma regarding mental illness affects both mental health service users and their family. The fact that all six mental health service users displayed poor compliance to medication is indicative of the stigma attached to mental illness and taking medication. There is a possibility that they feel that they are not in control of their lives when they take medication. They also probably prefer to ignore that they do have a problem.

The stigma of certain family members was quite evident in the statement by Mrs Jayshree when the social worker queried if the mental health service user help her to do anything, she said, *"No, no I didn't let him do anything."* This reinforces the stigma that mental health service user cannot work or do anything for themselves and that they need to be taken care of.

The fact that five family members interviewed indicated a need to place mental health service users back at Ekuhlengeni Care Centre, can also be associated with stigma and the general feeling that mental health service user should be locked away in an institution because they are mentally ill.

Sayce (2000) wrote that family members and partners need talks and information in order to assist them in identifying prejudiced views in themselves and others, as well as in revisiting and challenging them. It has been argued (Goffman, 1963 cited in Sayce, 2000) that the focal point of stigma is individual self-perception and affects micro level interpersonal relations, rather than extensive elimination from economic and social life. A national strategy to deal with discrimination against people with mental illness in New Zealand indicated that *"Years of research into public attitudes and stigma have not led to the development of*

effective models for change ...Whereas stigma attaches to the consumer, discrimination from actions of others. If placed in a human rights framework, there is clear evidence that widespread discrimination is exercised against people with mental illness. More importantly that framework also offers a well-tested methodology for identifying and resolving discriminatory practices (Mental health commission1997 cited in Sayce, 2000: p15)

The importance of destigmitizing mental illness is to ensure that mental health service users are part of the community in all aspects of their lives. This is supported by Sayce (2000) who wrote that people who are mentally ill are excluded in all areas of social and economic life, from holidays to work, driving cars to raising children. It has also been found (Read and Baker, 1996 cited in Sayce, 2000) that from 778 mental health service users who were surveyed, 47% had experienced verbal or physical abuse (e.g. eggs were thrown on them while being called a 'nutter', or dog faeces or paper that had been lit were pressed through their post box), 62% indicated that they had been treated unfairly by family or friends and 50% by health care services. Twenty five percent of the respondents indicated that they had been turned down by insurance or finance companies as a result of their mental condition.

The safety and security system

Both Mrs Reshma and Mrs Thandi experienced difficulties obtaining assistance from the police in their areas. According to Mrs Thandi when she initially phoned the police for assistance they did not respond, however when she called again recently and spoke to someone with the same surname as her, they responded and assisted with taking the mental health service user to Prince Mysheni Hospital. According to Mrs Reshma. she relayed the following *"The problems I had, the assaulting I took from him, I got no back-up with anybody, my neighbours came and stood here. We called for the police and I even phoned emergency, nobody came. If the police come they tell him "you must behave yourself" and they tell me if I want to go to court I must go to court and charge*

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him. When I went to the police station one day I went with full blood in my mouth when he bust me.......................they said even if they lock him up they will release him because he is psychiatric, they said I must go and speak to his doctor." Mrs Reshma came across as being very helpless because the system had in actual fact failed her, however her brother is protected by the very fact that he is mentally ill.

Cultural attitudes towards caring

Karp (2001) indicated that cultural attitudes towards care must also be taken into account. The boundaries of obligation between ill family members and their relatives are built into running of daily life. Our feelings and actions towards a family member who is ill has to be understood within cultural mandates and the meanings attached to care. It is presumed that people who are moral will look after their family irrespective of everything else. This expectation however conflicts with the cultural belief that we must be free to pursue our personal desires. It is believed however that caregivers are very distressed when they are unable to resolve this conflict. *"Mental illness, by its very nature, physically and emotionally exhausts family members"* (Karp, 2001: p234).

I believe that like the Americans, South Africans believe in community and individualism at the same time (Karp, 2001). It is expected that despite being committed to ourselves that we have to be committed to others at the same time. Caregivers are therefore confused about boundary lines. People therefore have the desire to be involved and uninvolved, connected and disconnected simultaneously. We are taught by a religious ethic to love our neighbours as we love ourselves. We therefore have to be kind, unselfish, charitable, and caring in all our relationships but more so towards those less fortunate than ourselves. The social structures that are created therefore reflect our cultural values (Karp, 2001).

Political decisions that impact on caring

The problems confronting caregivers on a daily basis is related to political decisions in terms of who deserves help and care and what institutions will provide it. Cultural values are reflected in the social structures we create. The family like any other institution in society echoes the wide cultural values and is profoundly shaped by them. If society chooses not to assist when a person needs help, the burden placed on family members is then drastically increased. We are at a point where when a person is disturbed and cannot cope with life, it is the relatives who grapple with the problem the best way they can. This places a burden on individuals that receives mixed messages from their culture about commitment to self and to others (Karp, 2001).

Recently, customary values of personal responsibility and self-reliance have been invoked as the foundation for reducing the role of government in caring for disadvantaged citizens (Bennet, 1993 cited in Karp, 2001). Government policies that view families as the final place of care are seen to be mirroring the correct role of family in nature however this view of the family is not in tune with the facts of family life, past or present (Karp, 2001). Karp (2001) emphasized that although support in families is significant to a lot of individuals, it does not always function in line with *"fixed rules implied by the idea that caring is "naturally" part of family relationships"* (Finch, 1989 cited in Karp, 2001:p253). Karp (2001) further explains that the notion held by governments that family should be the initial source of assistance to people who are in need, is out of sync with reality. The *"sense of obligation"* that characterizes relationships within families is not *"a set of ready-made moral rules, which all right-thinking people accept and put into practice"*. It develops over time and can vary in strength and *"its practical consequences are highly variable"* (Finch, 1989 cited in Karp, 2001:p253). Thornicroft and Tansella (1999) commented that in terms of the social and political area of each country there is a equilibrium that exist with regards to the care of mentally ill persons as well as the importance attached to their civil liberties on one hand and the lawful expectations of the general public that MHSUs must receive appropriate treatment on time, on the other hand.

The researcher is also aware that at the time the mental health service users were discharged there was pressure from the Department of Health to reduce the bed state at Ekuhlengeni Care Centre. According to Lazarus (2005: p66) *"Pressure to reduce beds may result in indiscriminate discharges, with patients discharged without careful assessment of their readiness for discharge, or of the availability or readiness of placement options to which discharge will take place."* This can therefore be attributed for the fact that mental health service user were not prepared well enough to ensure that they continue to remain stable after their discharge to their families. Obviously time did not permit for patients to be prepared individually based on their needs i.e. they were not prepared adequately to ensure that they understood the importance of them taking their medication, they were not provided with information to recognize when they are experiencing signs and symptoms of relapse and the fact that five of the six mental health service user were not meaningfully occupied indicates that they did not understand that being productive (even if it is at home) allows them to live a somewhat "normal" life.

HOW COULD THINGS BE BETTER? RECOMMENDATIONS FROM THE RESEARCH PARTICIPANTS

The participants were asked what could be done to improve conditions for them and their families. Mrs Zama, at the end of her tether, very bluntly replied, *"Readmit him."* Other family members suggested a range of interventions that they felt would be helpful. These included:

Regular Home Visits
The other family members indicated that the mental health service users and their relatives must be visited at least once a month. The relatives looking after

the mental health service user must be empowered with what to say to the mental health service user if they are engaging in disruptive behaviour or how to handle them. The family must be encouraged to go to the office/clinic for counselling and support. Mrs Grace said, *"They must check on the patient on a monthly basis and they must check on the people who are looking after them because sometimes these patients can be very aggressive and very stubborn. They need to empower the person who is looking after them, equip them with something to say that if a certain thing is happening, if the person acts in a certain way you need to know how to handle them."* Freeman (1996) reported that in the 1960s psychiatrists began to see many mental health service users at home, on home visits. This system was formulated for MHSUs who could not readily attend outpatient clinics. It was gauged that the evaluation of a case was more effective in a MHSU's familiar surroundings, with their relatives present. However, the home visits started to be conducted increasingly by social workers or psychiatric nurses. These home visits by mental health professionals developed in a number of ways, mainly in the work of crisis-intervention teams. This is further supported by Thornicroft and Tansella (1999: p64) who emphasized that *"In terms of the delivery of care, mental health services should make every attempt to ensure that in their interventions for patients they choose in each situation the least restrictive alternative. For example, a commitment to decrease the use of compulsory admission to hospital may necessitate the provision of realistic alternative services offering high degrees of support to patients at times of acute crisis, in settings which patients will accept on a voluntary basis, such as their own homes if intensive domiciliary treatment teams are available, or to other facilities such as crisis centers or respite houses."*

Adequate preparation of family

Further recommendations from families referred to their preparation to cope with their mentally ill relative. Suggestions such as the following were made:

"They need to empower the person who is looking after them, equip them with something to say that if a certain thing is happening, if the person acts in a certain way you need to know how to handle them." (Mrs Grace)

The importance of the statement made by Mrs Grace is reflected further in writings by (Vaughn & Leff, 1976 cited in Leff, 1997) that when relatives residing with the mental health service users are highly critical of them, it is more likely that a relapse of schizophrenia will take place. It was found that persons with mental illness respond to criticism from family members with social withdrawal or anger. If it is with anger, then conflict progresses to verbal or physical aggression because relatives are unable to defuse arguments. It is important that family members are educated about appropriate ways to cope with mental health service users.

Mr Sipho suggested that *"Educating and speaking to the families and informing families of the importance of taking medication "* was important when preparing families for mental health service users' discharge. This will lead to improved supervision by relatives to ensure mental health service users comply with taking their medication.

Adequate preparation of MHSU

They also indicated that mental health service users must be independent; because families cannot cope with them and if their families are not there no one else will take care of them. Further recommendations were that mental health service user must go on leave of absence with their relatives and the periods of the leave of absence must be gradually increased until discharge and when mental health service users are discharged, arrangements must be made for them to work so that they can be kept occupied after discharge. Mr Ayanda recommended mental health service users must be given *"strong"* medication when they are discharged.

Mr Kevin indicated that the male and female mental health service user use drugs in the hospital. Some staff overlook mental health service user skipping the fences to get drugs. He indicated that staff must be harder and sterner with the patients. He also suggested that there must be a library, and mental health service user must be occupied in occupational therapy. He also indicated that when mental health service users are discharged, there must be visits to them and their families by the social workers and the sisters from the clinics.

CONCLUSION

The overwhelming impression gained from the findings is that the discharge of MHSUs has been difficult for them and their families. The main areas of concern are poor compliance to medication and lack of professional support, which results in mental health service users presenting with poor hygiene, aggressive behaviour, and refusal to do any chores at home, inappropriate sexual behaviour, substance abuse as well as poor relationships and the lack of community support. No positive experiences were reflected by family members. However, MHSUs indicated increased freedom as being positive and in the case of Mr Kevin improved relations that he enjoyed with his nephews. These aspects have been discussed in this chapter.

Five of the six family members indicated that their relatives presented with problematic behaviour after discharge. This suggests that the process of determining the suitability of mental health service users for discharge back into the community needs to be reviewed. Prior to discharge mental health service user's relatives are encouraged to take their relatives on leaves of absence to assess the mental health service user's adjustment to the home environment; however, it would appear that this is not sufficient.

The following chapter, Chapter 5, presents the conclusions of the study and suggests recommendations for practice, policy and research.

CHAPTER SIX
CONCLUSIONS AND RECOMMENDATIONS

INTRODUCTION

This chapter brings this dissertation to a close. It begins by providing an overview of the research process and then goes on to summarize the main findings. It ends with recommendations from the MHSU, their families as well as recommendations from the researcher.

OVERVIEW OF THE RESEARCH PROCESS

This research into the experiences of MHSUs and their relatives upon the discharge of MHSUs from Ekuhlengeni Care Centre was conducted using a qualitative approach. The research was motivated by my experience as a senior social worker at this particular hospital. Part of my responsibility was to place MHSUs who have been assessed to be suitable for discharge, back with their family or in a residential facility. Knowing how they adapted to community living would be important and it was hoped that this research would help to answer questions in this regard.

An assumption underlying this study was that in implementing community care and de-institutionalisation, government was merely shifting its responsibility to families. This study aimed to assess whether community care was working and to ascertain if government should have concentrated on strengthening the resources and support structures in the community before embarking on a programme of de-institutionalisation.

The main aim of the research was therefore to investigate the experiences of adult Mental Health Service Users as well as their families upon discharge of service users, to their families in the Durban area, from Ekuhlengeni Care Centre from May 1999 to December 2001.

The ecosystems perspective formed the theoretical framework for this study. This perspective sees people and the environment as systems that interact and influence each other. This approach also sees people as constantly adapting, changing and are changed by the environment.

An exploratory descriptive research design was used and it was considered most appropriate as very few South African studies have concentrated on the experiences of service users once discharged from a long-term facility. Availability sampling was used and 10 interviews with MHSUs and family members were held. Data was collected by means of unstructured face to face interviews. An interpreter was used with regards to Zulu speaking service users and their families. Through the research the emphasis was on exploring the experiences of both the service users and their family members.

The final chapter provides a summary of the main findings of the study.

SUMMARY OF FINDINGS

The findings provide a clear picture of the many difficulties that service users and their families experience as well as the lack of support and services that exist for MHSUs and their relatives. The main findings are now discussed in terms of the objectives of the study.

Positive aspects of adapting to life in the community

The first objective of the research study was to explore the positive aspects of mental health service users' adaptation to living in the community. Sadly, it was of concern to note that the study showed that there were limited positive aspects.

At the micro and meso levels, the findings revealed that one of the respondents was able to be independent, taking responsibility for their own needs such as paying of bills, cooking, cleaning and ironing. Two of the service users did work

during the day and it appeared that they were motivated by the payment they received for the work done. However, majority of the MHSUs were not constructively occupied.

Challenges faced by mental health service users

The second objective of the study was to explore the challenges faced by service users in their adjustment to life in the community. The study revealed that MHSUs and their families experienced many challenges. These challenges were identified at different levels.

At a micro and meso level, MHSUs indicated that they faced challenges of accepting that it was not safe to be out of their homes late at night. They also had to learn how to interact and socialize appropriately in the community and with their relatives. Mental health service users also faced the challenge of complying with medication. At the macro level, it was clear that there was a lack of community and organisational support for MHSUs and their relatives. At the exo level the support from extended families, neighbours and friends were absent.

After care services

The third objective was to determine what after care services were being offered in the community. The results of the study indicated that at a micro level no services were being offered, for example one man had never been to the clinic since his discharge. There is a mismatch between the needs of the individual and the ability of the environment to support and meet those needs. This is also indicative of the fragmentation of services that exist at a meso and macro level. Services are not aligned and there is an obvious absence of policies clearly depicting the need for services to follow the mental health service user into the community. The mental health service user may be referred to the clinic however, if he chooses not to go to the clinic the clinic will not be aware of his referral and will therefore not follow-up. The need for formalized referral

procedures to the clinics and mental health societies is greatly needed. The feeling is that organizations do not complement each other's services but instead work in a vacuum.

It has also been established in the study that after care services is limited to medication management. It is also evident that there is no system in place to follow up on defaulters.

Experiences of the families of service users

The fourth objective was to explore the experiences of the families of service users when MHSUs return to their care. From discussions with relatives it was ascertained that when the MHSUs were initially discharged, their families saw positive changes in them however, this did not continue for long, as their functioning started to deteriorate. Family members had to deal with problematic behaviour such as refusal to do any chores at home, lack of personal hygiene, aggression, running away from home, inappropriate sexual behaviour, defaulting on treatment as well as substance abuse. These types of behaviour impacted negatively at a micro level as the MHSUs were not able to share good relations with family members.

This problem was obviously exacerbated in some instances by the families' lack of understanding of the MHSUs psychiatric condition. There was also a dire lack of support services to the family itself. Here again this is indicative that at a micro level no services are offered to the family resulting in a mismatch between the needs of the family and the ability of the environment to support and meet those needs.

All the MHSUs relatives indicated that the discharge of the service users added no value to the family. Instead it was assessed that rather than making positive contributions to the lives of their family members, MHSUs actually contributed negatively by being destructive, aggressive, and violent. They were amotivated

and presented with odd behaviour that community members brought to the attention of their families. They brought about disharmony to the lives of their relatives and compounded problems that relatives were already experiencing.

However, most of the family members interviewed indicated that MHSUs don't do anything for themselves, even maintaining their general hygiene is not taken for granted and they often neglect their appearance, and have to be reminded to bath.

Four of the mental health service users were discharged into the care of their aging parents or relatives who were not able to cope with them. These caregivers were especially vulnerable in light of the aggression displayed by certain MHSUs. The findings in this study were in keeping with other studies wherein it was found that majority of the caregivers are females.

It was evident in the interviews carried out with relatives that they found caring for their relatives to be stressful. This stress could very well be attributed to the lack of support offered to caregivers. The importance of the caregiver's role is not appreciated, as displayed by the experiences of Mrs Reshma. She felt blamed by the psychiatrist for MHSU's behaviour and he did not seem to appreciate her side of the story.

Family members had also experienced problems in obtaining assistance from the police, who it may appear, is not clear on their role in terms of MHSUs.

Findings also displayed that MHSUs also relapsed. This was more often than not, related to their poor compliance to treatment.
Ecosystems talks about goodness of fit however, it is evident from the study that this was not happening. This has resulted in the patients not being able to function well in the community. The environment has not been responsive in many ways, which has lead to challenges in terms of MHSUs' adaptation to living

in the community. The study clearly depicts that the environment has lacked services for MHSUs at all levels from the micro level to the macro level. In terms of the ecosystems perspective, one can conclude that in the absence of a balanced environment, service users had a very small chance of succeeding in the community from the onset. The environment was not conducive to assisting them in ensuring that they were successfully re-integrated into the community. There is an obvious lack of fit between MHSUs and the environment. The inability of MHSUs to adapt to their home environment has a ripple effect on all the other levels in the ecosystems model. They are seen to be problematic in the community, they are not independent economically, there is a demand for services that are already under pressure such as SAPS and the revolving door admissions and discharges place further strain on the health system and has major financial implications.

RECOMMENDATIONS FROM SERVICE USERS AND THEIR FAMILIES

The fifth objective was to obtain recommendations from the service users and their families on what areas should be focused on when conducting pre-discharge programmes at Ekuhlengeni Care Centre.

Family members made some useful suggestions regarding what would be helpful to them.

Home visits and communication skills

They felt that social workers or psychiatric nurses should visit relatives and MHSUs at least once a month. This will enable the professional to assess the behaviour of the service user as well as the care provided by the family. Skills should also be imparted to relatives in terms of communicating to service users when they present with difficult types of behaviour. Relatives should be encouraged to seek counselling and support as and when they need it.

Coping skills and medication compliance

Further recommendations from families referred to their preparation to cope with their mentally ill relative. It was indicated that relatives need to be empowered with the skills to defuse arguments and to generally be educated about appropriate ways to cope with mental health service users.   Relatives must be educated about the importance of MHSUs taking medication, which can lead to improved supervision ensuring that service users comply with treatment.

Ability to live independently

Family members also indicated that mental health service users must be independent, because families cannot cope with them and if their families are not able to care for them they should be able to live independently.

Leave of Absence and work arrangements

Further recommendations were that mental health service users must go on leave of absence with their relatives, the periods of the leave of absence must be gradually increased until discharge, and when mental health service users are discharged, arrangements must be made for them to work so that they can be kept occupied after discharge.

Staff attitudes and Occupational Therapy

It was also suggested that staff at psychiatric facilities should not overlook mental health service users skipping the fences to get drugs. Instead staff must be harder and sterner with the patients. There were also suggestions that there be a library where MHSUs can keep busy by reading books and that mental health service users must be occupied in occupational therapy.

RECOMMENDATIONS FOR PRACTICE

Arising from the study, a number of recommendations can be made. These are discussed in terms of the MHSU, the family, the community and policy.

Mental health service users

At a micro level it is imperative that once mental health service users are diagnosed with a mental illness, they be educated about the illness. Aspects such as the causes and nature of the condition, the importance of them taking medication, and the signs and symptoms of relapse so they can seek help immediately, should be included in such education programmes. Very often mental health service users after many years of illness are still ignorant about their condition as well as the significance of taking their medication religiously.

MHSUs must be involved in a support group and this should happen at the onset of their illness. These groups can be run by mental health societies as well as clinics in the area. The groups will be therapeutic, allowing service users to gain information to deal with the challenges they experience on a daily basis.

At the institutional level, efforts must be made to ensure that when MHSUs are being discharged, they will be occupied in a sheltered workshop. Efforts should also be made to advocate for greater access to the job market for those individuals who will be able to cope.

It is imperative that highly individualized discharge plans be formulated for mental health service users who are found to be suitable for discharge and discharges should not be done purely to reduce the bed state. Discharging mental health service users back into the community is a process and should not be attached to timeframes but dependent on mental health care service user readiness to go back into the community and the readiness of the community to provide adequate support.

Family

The family is a very important part of the microsystem. It is important that they are adequately prepared for the discharge of their family members. It is also necessary that families of mental health service users are educated about their

relatives' condition and the importance of their support in ensuring that their relative complies with treatment. It is also imperative for family members to be educated about the signs and symptoms of relapse so they can seek assistance as soon as possible (if the service user does not). Another aspect that family members need to be educated on is the importance of compliance to medication.

MHSUs as well as their families must be involved in support groups once their relative has been diagnosed with suffering from a mental illness. The support groups will be therapeutic and will assist in alleviating the stress they experience in caring for their relatives. The support groups will also facilitate the sharing of ideas, advice as well as coping mechanisms.

Families must be empowered about the assistance they are entitled to, from the police when their relatives become uncontrollable due to their aggressive and violent behaviour. Presently they do not get much assistance from the SAPS when they attempt to seek assistance contributing to their feelings of helplessness. It is also imperative that the assistance required by family members is made available as and when it is required.

Education, must also be provided to families, on coping skills in terms of communicating appropriately with the service users and not in ways that will provoke them to become aggressive in any way. For example, families need to be taught how to handle mental health service users when they become difficult and not to react in a manner that will agitate the mental health service users and aggravate the situation. They should also be educated on how to handle mental health service users in the event that they begin to display aggressive behaviour. Here again is the importance of the family to have an understanding of the mental health care service user's illness because the manner in which they relate to the mental health care service user affects their (mental health service users) behaviour. According to Lazarus (2005:p66) one of the concerns expressed with regards to de-institutionalisation is the inadequate time and effort

utilized to prepare the families of mental health care service user to *"accept and manage the discharged individual in the home environment."* It is also important to include families in the pre-discharge programme of their relative.

Community

There is a great need for education targeting resources in the community such as the SAPS in terms of their role and the type of assistance that they can provide to the families who experience problematic behaviour with their mentally ill relative.

Home visits by social workers and nursing sisters in primary health care clinics to mental health service users and their families must be carried out in order to assess the relationships at home. It is therefore important for more social workers to be employed at community level to ensure adequate monitoring of service users, to be available to intervene if there are any problems being experienced in terms of communication in the home and to be available to the patient and family as a source of support.

At the level of the exosystem the extended family and community members must be educated to understand their role in ensuring MHSUs adjust well to being back in the community and also maintain their functioning in the community, as well as the assistance they can provide to the family.

At the macro level awareness campaigns must be conducted on a wide scale to eradicate the stigma that is associated with mental illness. The aim should be to see mental illness like any other chronic condition. The awareness campaigns must target health care workers and the public. Even though there has been a move to integrate psychiatry into primary health care, stigmatisation of these patients is very much alive and health care workers themselves promote this. Mental health service users must be accepted as any other member of society.

Recommendations for policy

At a meso level, it is extremely important for all stakeholders i.e. the institutions, the Department of Health, the Department of Welfare and the relevant NGOs to work together in formulating a referral process. This referral process will include tracking service users discharged from the institutions into the community as well as the provision of appropriate services that will ensure the continued stable functioning of service users in the community. This formalized system of referral will contribute further in ensuring medication compliance and treatment.

Concerted efforts need to be made by the different government departments to ensure that programmes are in place to provide opportunities for work and vocational activities. Government must ensure, through legislation that vocational and job opportunities for service users are addressed and businesses should be held responsible for not making provision for the employment of MHSUs. Employment of the disabled should not be understood largely as employment of the physically disabled as this results in the MHSU being disadvantaged.

Education and the possibility of implementing a system that is similar to that of the buddy system for patients diagnosed with TB must be explored for mental health service users in order to alleviate the problem of poor compliance to medication.

There is also a dire need for residential facilities in the community ranging from half-way houses to group homes. It is important that these resources are strengthened in order to support community-based care. The de-institutionalisation process in KZN should have been accompanied by significant efforts to increase these resources, as was the case in Gauteng. To date since de-institutionalisation commenced in KZN a very small number of these facilities have been established, if any.

Government must ensure that adequate community resources are in place for MHSUs and their families. This should have been considered prior to government embarking on de-institutionalisation. Many communities, both rural and urban, are lacking in resources and efforts need to be made to resolve this issue. It is unjust to expect such communities to take total responsibility for caring for people with mental health problems. Mental health service users form part of the vulnerable group and government should do everything in its power to ensure that service users have all the necessary resources and support in the community to ensure their optimal functioning in the community.

Services to mental health services users are very fragmented. This must be resolved by fostering closer relationships and co-operation between the various government departments, NGOs (Non-governmental organisations), CBOs (Community based organisations), and FBOs (Faith based organisations). This will ensure that a well co-coordinated service is being provided to mental health service users. The various role players should have clear guidelines as to where they fit in regards to the care of the MHSU and their roles should complement each other.

Government must ensure that when patients are discharged from the community that the funds also follow the patient into the community. Mental health must also be regarded as a priority just as TB and HIV/AIDS. This can be done by increasing the budget allocation to mental health. It also needs to be realized that the mental health of the citizens in this country, as in any other country, are interlinked with their physical health. In fact, it is very often that the stress and other social problems that people experience lead to medical conditions such as hypertension as well as suicide attempts. It is important to give mental health the recognition that it deserves and the financial resources required to maintain a country of citizens with sound minds and inevitably reducing those medical conditions caused by stress.

CONCLUSION

"The greatness of a country is accurately measured not by its military victories and the personal fortunes of its wealthiest citizens, but by the degree to which all its citizens and residents are able to freely exercise their economic, social, cultural, civil, and political rights, and to flourish within a just society mindful of the good of all persons, including the weakest and most vulnerable" (Normand, 2003).

In respect of people with mental health problems, South Africa is failing dismally. Despite the good intentions of the legislation and policy, people with mental health problems and their families continue to struggle. This dissertation has explored the experiences of mental health service users and their families and the research has highlighted the many problems that exist. In any plan to improve the quality of life of mental health service users, their voices need to be heard. It is hoped that the voices of the people who participated in this study will be heard and that this will contribute to a more caring system of service delivery. Let us learn from international experience and adapt the lessons for our conditions.

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