

Perspectives of male mental health service  
users on their community integration  
following participation in a residential-based  
rehabilitation programme

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## ABSTRACT

Current re-engineering of primary mental health care in South Africa is directed towards providing a continuum of care for people with serious mental disorders in order to relieve the cost and resource burden of long-term hospitalisation. In the Western Cape, Healthcare 2030 has been adopted as the guiding vision for health system reform. Residential-based rehabilitation programmes have been introduced to assist mental health service users to improve their functioning in occupations of daily life so that they are better equipped to cope with community living. **Problem:** There is limited South African occupational therapy research into male mental health service users' perspectives on the contribution that residential-based rehabilitation programmes makes to their community integration, despite the high numbers of males using the service. **Purpose:** To inform public mental health services on the contribution of a residential-based rehabilitation programme to the community integration of men with serious mental disorders. **Research question:** How does participation in a residential-based rehabilitation programme contribute to the community integration of men with serious mental disorders? **Objectives of the study:** To identify what men with serious mental disorders consider community integration to be, and to describe the key elements within the residential-based rehabilitation programme that influenced their community integration. **Research design and methodology:** An instrumental case study design was used to guide the research methodology and five male participants were identified through purposive sampling. Observations, semi-structured interviews, community maps and document analysis were used as data collection tools. Data was audio-recorded and transcribed for inductive and thematic cross-case analysis. Ethical principles of beneficence, autonomy and non-maleficence were upheld throughout the research process. **Findings:** One theme and three categories emerged in the findings. The theme, 'It's a catch-22 situation', comprises three categories, namely: 'It's not just what you call it'; 'There's no one size for all'; and 'It's tricky choosing between places to go

and things to do'. **Conclusion:** Male mental health service users who participate in a residential-based rehabilitation programme will be better prepared for community integration if they are involved in co-constructing their recovery plan so that it is more personalised.

**Key words:** community integration, occupation, mental health care, recovery

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# TABLE OF CONTENTS

DECLARATION.....	I
ABSTRACT.....	II
ACKNOWLEDGEMENTS.....	IV
TABLE OF CONTENTS.....	VI
LIST OF FIGURES.....	X
LIST OF TABLES.....	X
ABBREVIATIONS.....	XI
DEFINITION OF TERMS.....	XII
<b>CHAPTER 1: INTRODUCTION.....</b>	<b>1</b>
1.1 INTRODUCTION.....	1
1.2 BACKGROUND TO THE STUDY.....	2
1.3 SITUATING THE RESEARCHER: PERSONAL INTEREST IN THE STUDY.....	3
1.4 RATIONALE FOR THE STUDY.....	4
1.4.1 <i>Global context and mental health</i> .....	4
1.4.2 <i>Finding appropriate care models</i> .....	5
1.4.3 <i>Getting the mental health service mix right for community integration</i> .....	6
1.4.4 <i>Social determinants of health</i> .....	7
1.4.5 <i>Barriers to mental health care</i> .....	8
1.4.6 <i>Human occupation and residential-based programmes</i> .....	9
1.4.7 <i>Community integration and related services</i> .....	10
1.5 RESEARCH PROBLEM.....	10
1.6 RESEARCH PURPOSE.....	11
1.7 RESEARCH QUESTION.....	11
1.8 RESEARCH AIM.....	11
1.9 RESEARCH OBJECTIVES.....	11
1.10 SUMMARY.....	12
1.11 OVERVIEW OF THE RESEARCH REPORT.....	12
<b>CHAPTER 2: LITERATURE REVIEW.....</b>	<b>13</b>
2.1 INTRODUCTION.....	13
2.2 PSYCHOSOCIAL REHABILITATION, RECOVERY AND COMMUNITY INTEGRATION OF PEOPLE WITH SERIOUS MENTAL DISORDERS.....	13
2.2.1 <i>Definitions of health and psychiatric disability</i> .....	13
2.2.2 <i>Psychosocial rehabilitation and recovery</i> .....	15
2.3 MENTAL HEALTH SERVICE TRANSFORMATION IN THE WESTERN CAPE, SOUTH AFRICA.....	19
2.3.1 <i>Mental health service history</i> .....	19
2.3.2 <i>Mental health service policy</i> .....	20
2.3.3 <i>Mental health services in the Western Cape</i> .....	20

2.3.4	<i>Mental health service models in the Western Cape</i> .....	21
2.3.5	<i>Effectiveness of care for MHSUs</i> .....	22
2.4	OCCUPATION: ITS ROLE IN RECOVERY AND COMMUNITY INTEGRATION .....	24
2.4.1	<i>Categorisation of occupations</i> .....	24
2.4.2	<i>Occupational choice and engagement</i> .....	25
2.5	GENDER AND MENTAL HEALTH SERVICE USERS.....	26
2.5.1	<i>Men and mental disorders</i> .....	26
2.5.2	<i>The occupational engagement of men</i> .....	27
2.6	SUMMARY .....	29
<b>CHAPTER 3: RESEARCH DESIGN .....</b>		<b>30</b>
3.1	INTRODUCTION.....	30
3.2	PHILOSOPHICAL STANDPOINT .....	30
3.3	TRADITION OF INQUIRY .....	31
3.4	RESEARCH CONTEXT .....	32
3.5	RESEARCH SITES.....	34
3.5.1	<i>Gateway residential-based rehabilitation facility</i> .....	34
3.5.2	<i>Referral pathways to and from Gateway</i> .....	35
3.5.3	<i>Identification of research site</i> .....	36
3.5.4	<i>Gateway programme</i> .....	37
3.5.5	<i>Gaining entry</i> .....	37
3.6	STUDY POPULATION AND SAMPLING .....	38
3.6.1	<i>Inclusion criteria</i> .....	39
3.6.2	<i>Exclusion criteria</i> .....	40
3.6.3	<i>Participant profiles</i> .....	41
3.6.4	<i>Informed consent</i> .....	41
3.7	DATA GENERATION METHODS .....	42
3.7.1	<i>Interviews</i> .....	43
3.7.2	<i>Resource mapping</i> .....	44
3.7.3	<i>Observations</i> .....	44
3.7.4	<i>Journaling</i> .....	45
3.7.5	<i>Document review</i> .....	45
3.8	DATA MANAGEMENT.....	46
3.9	DATA ANALYSIS .....	46
3.9.1	<i>Within-case analysis</i> .....	47
3.9.2	<i>Cross-case analysis</i> .....	48
3.10	ENSURING TRUSTWORTHINESS .....	48
3.10.1	<i>Credibility</i> .....	49
3.10.2	<i>Transferability</i> .....	49
3.10.3	<i>Dependability</i> .....	50
3.10.4	<i>Confirmability</i> .....	51
3.11	ETHICAL CONSIDERATIONS.....	51
3.11.1	<i>Autonomy and respect</i> .....	51
3.11.2	<i>Non-maleficence</i> .....	52
3.11.3	<i>Beneficence</i> .....	53
3.11.4	<i>Justice</i> .....	54

3.12	SUMMARY .....	54
<b>CHAPTER 4:</b>	<b>THE PARTICIPANTS .....</b>	<b>56</b>
4.1	INTRODUCTION.....	56
4.2	PARTICIPANTS .....	56
4.2.1	<i>Mikael</i> .....	56
4.2.2	<i>Bolo</i> .....	58
4.2.3	<i>Gershwin</i> .....	60
4.2.4	<i>Emmanuel</i> .....	62
4.2.5	<i>Dan</i> .....	64
4.3	CONCLUSION .....	66
<b>CHAPTER 5:</b>	<b>FINDINGS .....</b>	<b>67</b>
5.1	INTRODUCTION.....	67
5.2	THEME: 'IT'S A CATCH-22 SITUATION' .....	67
5.3	CATEGORY 1: 'IT'S NOT JUST WHAT YOU CALL IT' .....	69
5.4	CATEGORY 2: 'THERE IS NO ONE SIZE FOR ALL' .....	73
5.5	CATEGORY 3: 'IT'S TRICKY CHOOSING BETWEEN PLACES TO GO AND THINGS TO DO' .....	83
5.6	SUMMARY .....	90
<b>CHAPTER 6:</b>	<b>DISCUSSION .....</b>	<b>91</b>
6.1	INTRODUCTION.....	91
6.2	THE GAP IN ACCESS TO PUBLIC MENTAL HEALTH TREATMENT .....	91
6.3	ACCESS TO MENTAL HEALTH TREATMENT IN PHC SERVICES .....	92
6.4	MENTAL HEALTH PROMOTION FOR COMMUNITY INTEGRATION.....	94
6.4.1	<i>Shift of care from institutions to community-based services</i> .....	95
6.4.2	<i>Mental health literacy for social inclusion</i> .....	98
6.4.3	<i>Advocacy, policy-making and self-help initiatives</i> .....	99
6.5	OCCUPATION-BASED PRACTICE FOR COMMUNITY INTEGRATION .....	101
6.5.1	<i>Community integration through work occupations</i> .....	103
6.6	A RECOVERY-BASED VISION FOR RESIDENTIAL-BASED FACILITIES.....	105
6.7	SUMMARY .....	108
<b>CHAPTER 7:</b>	<b>RECOMMENDATIONS, LIMITATIONS AND CONCLUSION .....</b>	<b>109</b>
7.1	RECOMMENDATIONS.....	109
7.1.1	<i>Recommendations for practice: step down/step up programme</i> .....	109
7.1.2	<i>Recommendations for practice: service platform</i> .....	110
7.1.3	<i>Recommendations for research</i> .....	111
7.2	LIMITATIONS .....	111
7.3	CONCLUSION .....	112
<b>REFERENCES.....</b>		<b>114</b>
<b>APPENDICES.....</b>		<b>133</b>
APPENDIX A	LITERATURE SEARCH .....	133
APPENDIX B	UCT HUMAN RESEARCH ETHICS APPROVAL .....	134
APPENDIX C	WESTERN CAPE GOVERNMENT ETHICS APPROVAL.....	135
APPENDIX D	PARTICIPANT INFORMATION SHEET .....	136
APPENDIX E	PARTICIPANT SIGNED CONSENT FORM.....	141

APPENDIX F	PRELIMINARY INTERVIEW SCHEDULE .....	145
APPENDIX G	RESOURCE MAP SAMPLE .....	148
APPENDIX H	DOCUMENT LIST.....	149
APPENDIX I	DATA ANALYSIS SPIRAL TABLE .....	150
APPENDIX J	AUDIT TRAIL .....	151
APPENDIX K	INTERPRETATION OF RAW DATA .....	153
APPENDIX L	LIST OF FOOTNOTES.....	155

## **LIST OF FIGURES**

Figure 3.1: Western Cape Province .....	33
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## **LIST OF TABLES**

Table 3.1: City of Cape Town .....	33
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Table 3.2: List of participants .....	41
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Table 5.1: Overview of the findings .....	67
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## **ABBREVIATIONS**

ACT	Assertive Community Treatment
APH	Associated Psychiatric Hospitals
CBR	Community-Based Rehabilitation
CHC	Community Health Centre
LMICs	Low and Middle Income Countries
MHCA	Mental Health Care Act 17 of 2002
MHSU	Mental Health Service User
MHSUs	Mental Health Service Users
NPO	Non-Profit Organisation
OPD	Outpatient Department
PHC	Primary Health Care
PSR	Psychosocial Rehabilitation

## DEFINITION OF TERMS

**Community integration:** is the ability of a person to live, work and enjoy his or her free time and day-to-day occupations within a community setting (Radomski & Latham, 2008, p.80).

**Deinstitutionalisation:** is the practice of caring for individuals in their community of choice, rather than at institutions (Galheigo, 2011, p.62).

**Step down/step up facility:** is a residential-based placement that offers a range of short to medium term treatment and rehabilitation services aimed at promoting independence, decreasing hospital admissions or avoiding unnecessary admissions. Services can be offered in a hospital or special unit and the facility is also referred to as a halfway house or intermediate care facility (Department of Health, 2014, p.2).

**Serious mental disorder:** refers to persistent clinically significant disturbances in an individual's thinking, emotions, relationships and behaviour that reflects a dysfunction in the psychological, biological or developmental processes underlying mental functioning. Serious mental disorders are associated with significant distress or disability in social, occupational or other important activities (American Psychiatric Association, 2013, p.20). Diagnoses considered to be serious include schizophrenia, bipolar disorder and severe depression (Townley, Kloos, & Wright, 2009, p.2).

**Mental health:** is part of overall health and implies that individuals can form and maintain relationships with others, perform in expected social roles and manage change and emotions. Mental health is influenced by social, biological, psychological and environment factors within the individual and their social world (Bhugra, Till, & Sartorius, 2013, p.3).

**Mental health care user:** is "a person receiving care, treatment and rehabilitation services or using a health service at a health establishment aimed at enhancing the mental health status of a user, state patient and

mentally ill prisoner...” (Mental Health Care Act 17 of 2002, South African Government, 2002, p.10).

**Occupation:** “is a type of relational action through which habit, context, and creativity are coordinated toward a provisional yet particular meaningful outcome that is always in process; the type of occupation is defined by the particular combination of habit, context, creativity and provisional outcome”(Cutchin, Aldrich, Bailliard, & Coppola, 2008, p.164).

**Occupational engagement:** encompasses all that one does to involve oneself or to become occupied (Polatajko et al., 2007, p.24).

**Recovery:** involves the development of new meaning and purpose in one’s life by moving beyond the role of being a patient with a mental illness. Personal recovery is individually defined and includes hope, identity, personal responsibility and meaning. Clinical recovery in contrast focuses on symptom reduction and mental health service treatment (Slade, 2010, p.206).

# **CHAPTER 1: INTRODUCTION**

## **1.1 Introduction**

Recovery for persons with enduring mental disorders involves the development of new purpose and meaning in life. This is facilitated by mental health services that offer the four key recovery values of hope, person orientation, person involvement and choice over the longitudinal course of their illness (Slade, 2009; Farkas, 2007). Creating and maintaining hope for the future is a necessary component of recovery oriented programmes. Services which develop the personal talents and strengths of MHSUs as opposed to focusing on their deficits are appreciated by MHSUs. Through the promotion of access to resources and environments external to the mental health service, significant roles can be acquired which speak to the interest of the MHSU as a person and not only a patient. Person involvement refers to MHSUs' involvement in designing and delivering mental health services. This is crucial for the self-identity and the development of a sense of empowerment of the MHSU. Choice and partnership is a fundamental recovery value as it provides the MHSU with agency to determine their own recovery goals (Farkas, 2007, p.71). Successful community integration is indicated as a recovery strategy to keep people with severe mental disorders mentally stable, out of hospital and living productive, meaningful and socially connected lives (Gulcur, Tsemberis, Stefancic, & Greenwood, 2007; Farkas, 2007).

Residential-based rehabilitation programmes are aimed at enabling and supporting such a recovery trajectory. These programmes are usually offered over a three to nine month period and focus on preparing mental health care users (MHCUs) to live in their communities. This study reports on the perspectives of men with serious mental disorders regarding their

participation in a residential-based rehabilitation programme and its contribution to their recovery and subsequent community integration.

## **1.2 Background to the study**

Mental health is increasingly being recognised as a public health issue in South Africa (Ritsuko Kakuma, Lund, Kleintjes, & Flisher, 2010). Public mental health services in South Africa are still predominantly offered through inpatient services in the 23 psychiatric hospitals across the country (Ritsuko Kakuma et al., 2010; Kleintjes, Campbell-Hall, Petersen, Funk, & Flisher, 2008). The Mental Health Care Act (MHCA) (Act 17 of 2002) set the scene for South Africa to shift away from legislation that promoted racially segregated mental health care during the apartheid era<sup>1</sup> to legislation that emphasises human rights (Gillis, Robertson, Zabow, & Stein, 2012). Mental health reform resulting from this involved a deinstitutionalisation process. This process has led to shorter periods of hospital admission, which focus on the management of acute symptoms mainly through the use of psychotropic medication. Shorter admissions have created a treatment gap in access to rehabilitation services in and out of hospital (Botha, Koen, Joska, Hering, & Oosthuizen, 2010).

In 2008 a step down/step up facility, Gateway<sup>2</sup> was introduced in the Western Cape as an intermediary inpatient residential-based rehabilitation service. This level of service is positioned between specialist, hospital-based psychiatric care and discharge, to clinic-based primary care services (Gillis et

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<sup>1</sup> Apartheid is the Afrikaans word for “separateness”. It was the racial, social policy introduced by the National Party government of South Africa in 1948 and it was upheld until 1994 (Little, 2015). The late Nelson Mandela (1993) had this to say about apartheid in his Nobel lecture: “We speak here of the challenge of the dichotomies of war and peace, violence and non-violence, racism and human dignity, oppression and repression and liberty and human rights, poverty and freedom from want.”

<sup>2</sup> Pseudonym used for the step down/step up facility referred to in this study. Step down refers to referral from a psychiatric hospital to Gateway and step up refers to referral from a community health centre to Gateway.

al., 2012). While this intermediary service is still not geographically accessible to all mental health service users (MHSUs), it is a part of the health system reform that can help to narrow the gap between mental health services at hospital and primary levels of care (Kakuma et al., 2010; Petersen, Ssebunnya, Bhana, & Baillie, 2011). Current residential-based rehabilitation programmes offered in the public sector do not specifically address the needs of men who are important role players in society (Jewkes, Sikweyiya, Morrell, & Dunkle, 2009; Morrell, 2007); yet men constitute the majority of MHSUs in the Western Cape (Associated Psychiatric Hospital, 2008). To date, no studies have been done on evaluating the contribution that Gateway makes to the recovery and community integration of its male MHSUs.

### **1.3 Situating the researcher: personal interest in the study**

I am a female, coloured<sup>3</sup>, Muslim who grew up on the Cape Flats<sup>4</sup>. Through my training as an occupational therapist I have worked in a range of public sector mental health settings used mostly by MHSUs from disadvantaged communities.

My interest in the topic of community integration of male MHSUs arose out of my supervision of senior occupational therapy students placed at a step down/step up facility. I noticed that more men were using the service than women. This is supported by records, which indicate that 80% of persons referred to residential-based rehabilitation programmes in the Western Cape are men (Western Cape Department of Health, 2011). This raised my

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<sup>3</sup> Coloured refers to South Africans who have creolised identities, which are shaped and re-shaped by current and historical experiences that bind them together. These include slavery and oppressive treatment during apartheid (Erasmus, 2000, p.84).

<sup>4</sup> Cape Flats refers to an expansive low lying flat area outside of the Cape Town city centre to which 'non-whites' were forcibly moved during apartheid. Within the Cape Flats there are further racial, economic and spatial divisions between coloured communities and African townships (Standing, 2003).

curiosity and I wondered how their admission to Gateway influenced their experience of community integration.

Apartheid contributed towards historical constructions of masculinity, which endorsed the use of violence in public and private spaces. On the Cape Flats the incidence of violence, poverty, unemployment, substance abuse and hardship is frequently attributed to the males in my community. While there are organisations dedicated to addressing the needs of marginalised groups such as women, children and the disabled, I wonder about the rights of and place of men in our nation. The challenges facing South African society require that both men and women be involved in reconstructing masculinities in order to promote equitable gender relationships (Jewkes et al., 2009; Morrell, 2007).

The introduction of residential-based rehabilitation services for MHSUs from across the Western Cape Province raised questions for me as to how men view the programme and whether it contributes to their sense of community integration. My interest in how this marginalised group constructs meaning through their experiences leans me to favour a constructivist philosophical standpoint (Morrow, 2007). My choice to conduct qualitative research is in line with my belief that there are multiple realities related to living with a mental disorder that are worth reporting on.

## **1.4 Rationale for the study**

### **1.4.1 Global context and mental health**

Mental disorders have increased in ranking in the top ten public health priorities globally. According to the World Health Organisation (Kessler et al., 2009), unipolar major depression will be the second leading diagnosis in disease burden in the year 2020. Mental disorders account for a significant burden of disease in many societies (Patel, Flisher, Hetrick, & McGorry,

2007; Prince et al., 2007; Whiteford et al., 2013). The global effect of poor mental health has been translated into a projected economic output of US \$16 trillion over the coming 20 years (Whiteford et al., 2013).

Community-based rehabilitation (CBR) “is a strategy within general community development for the rehabilitation, poverty reduction, equalisation of opportunities and social inclusion of all people with disabilities” (World Health Organisation, 2010:24), inclusive of those with mental disorders. The CBR principles of equality, social justice, solidarity, integration and dignity are embedded in human rights legislation. The five components, which make up the CBR matrix, are health, education, livelihood, social and empowerment components. While the focus of the first four development components is on the multisectoral emphasis of CBR, the final component focuses on empowering people with disabilities so that they can exercise their human rights to access the other four areas in order to improve their quality of life. More research is needed on the perspectives of MHSUs on the social and structural contexts within which they live and how this impacts on their social inclusion and access to opportunities.

#### **1.4.2 Finding appropriate care models**

While poor mental health equates to significant personal and economic costs there remains a gap in access to treatment. This treatment gap results in a violation of the human rights of people with mental disorders (Chisholm et al., 2007; Lund et al., 2010; Whiteford et al., 2013). The treatment gap has been attributed to stigma, discrimination, limited human and financial resources, inequitable resource distribution and insufficient resource use (Chisholm et al., 2007). Addressing the treatment gap requires the prioritisation of public mental health initiatives geared towards the prevention and treatment of mental disorders.

The effective rehabilitation of people with severe mental disorders is one aspect of treatment that is underresearched. There is currently no conclusive

evidence that specific therapeutic interventions improve social functioning or alleviate negative symptoms for people with severe mental disorders (Cook, Chambers, & Coleman, 2009). Rehabilitation has different meanings to different service providers and different service users making it a difficult process to measure (Schofield, 2006). Health professionals view the purpose of rehabilitation as facilitating an individual's optimal level of independent functioning (Zietsman & Casteleijn, 2014). Knowing more about the perspectives of MHSUs on their rehabilitation experiences will strengthen efforts to close the treatment gap and align services with users' actual needs.

### **1.4.3 Getting the mental health service mix right for community integration**

Traditionally, individuals with serious mental disorders have been institutionalised in hospital or residential settings for treatment when they are acutely ill. They either stay there on a long term basis or once they are considered stable enough they are discharged back into their communities (Townley et al., 2009; Radomski & Latham, 2008). Contemporary mental health interventions advocate deinstitutionalisation and community-based care (Davidson et al., 2001; Francisco & Carlson, 2002; Gillis et al., 2012; Kleintjes, Campbell-hall, Petersen, Funk, & Flisher, 2008; Macpherson & Gregory, 2007). Deinstitutionalisation has made mental disorders more visible in society and with it comes opportunities to understand the complexities of mental disorders (Bolton, 2008).

Primary health care<sup>5</sup> (PHC) is the first level of contact of individuals, the family and community with the public health system. It is the first element in a health care process that seeks to bring health care as close as possible to where people live and work (World Health Organization, 2008a, p.18). A PHC orientated service mix of hospital and community-based care provides

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<sup>5</sup> The PHC approach as defined according to the Alma Ata Declaration of 1978 (World Health Organization, 2008)

MHSUs with a range of options including acute inpatient care, ambulatory care with specialist support, out-patient clinics, community mental health teams, service user support and advocacy groups, long term community-based residential care and alternative forms of employment and occupational engagement options (Thornicroft, 2013). There is currently a gap in the literature regarding MHSUs' experiences of the mental health service mix available to them, in particular the interface between a residential-based rehabilitation facility and community integration.

#### **1.4.4 Social determinants of health**

Recent studies have shown a link between mental disorders and poverty, highlighting the need to know more about, and address the social determinants of mental ill-health (Gouws et al., 2010; Lund, 2012; Lund et al., 2010). A systematic review of poverty and common mental disorders in low and middle income countries (LMICs) was conducted by Lund et al. (2010). The epidemiological literature spanned 19 years and they found that the social and economic conditions of poverty are linked with common mental disorders in LMICs and that chronic poverty is maintained in a complex and multidimensional way (Lund et al., 2010, 2011). Their review concludes that mental health must be included in development studies and international targets and cannot only be on the agenda of mental health services.

MHSUs utilising public mental health services in the City of Cape Town, in the Western Cape Province come from areas across the Cape Flats which are plagued by poverty, gangsterism, substance and alcohol abuse, unemployment, delinquency, teenage pregnancy, school dropout and violence (Western Cape Department of Health, 2014). The communities within which MHSUs live are characterised by economic and social inequalities, which impact on their ability to successfully integrate and stay mentally well (Ritsuko Kakuma et al., 2010).

Given the depth of poverty and social inequality<sup>6</sup> in South Africa, health professionals have been encouraged to explore the range of mental health services that could be made available in resource-poor communities (Draper et al., 2009; Ritsuko Kakuma et al., 2010; Inge Petersen & Lund, 2011). The structural poverty and harsh social realities faced by the majority of the South African population draws attention to the shifts that are needed in health service delivery so as to facilitate the move towards (mental) health promotion and (mental) illness prevention (Faydi et al., 2011). These shifts cannot be achieved without understanding more about the ways in which MHSUs go about managing their recovery and community integration in contexts such as those that exist on the Cape Flats.

#### **1.4.5 Barriers to mental health care**

Historically South African mental health care has competed with general health care for access to financial, human and other resources required for mental health service delivery. The literature suggests that MHSUs have not enjoyed the same attention as people with physical disabilities (Kleintjes & Lund, 2010). Although the constitution of post-apartheid South Africa upholds the rights of disabled people, MHSUs continue to be marginalised as a result of the stigma and prejudice associated with having a mental disorder (Kleintjes, Lund, & Swartz, 2013).

A review of the literature showed that policy makers also exclude MHSUs. Some of the barriers to MHSU participation in mental health policy

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<sup>6</sup> The Gini co-efficient for South Africa is currently 0.70 (Barrientos et al., 2013). This ratio is used to measure inequality in a country based on income distribution. The higher the number the greater the inequality. South Africa has the worlds' highest Gini coefficient. There is currently debate around whether South Africa should have two calculations; one based on income from work and one which considers income inclusive of social grants (Rossouw et al., 2010). 35% of the population live on ZAR116 per day.

development were identified as follows: stigma, social discrimination, poverty, low priority of mental health, poor recovery and inadequate community supports (Kleintjes, Lund, Swartz, Flisher, & The Mhapp Research Programme Consortium, 2010; Inge Petersen & Lund, 2011). In the Western Cape Province, Healthcare 2030, the health re-engineering policy directive seeks to address some of these identified barriers. The policy intention is to develop public mental health services through equitable resource distribution (Western Cape Department of Health, 2014). The inclusion of MHSU perspectives on the uptake of community-based mental health services offers an ideal opportunity for MHSUs to provide input into translating policy into relevant programmes.

#### **1.4.6 Human occupation and residential-based programmes**

Scrutiny of the elements of community integration points to an occupational dimension in understanding what MHSUs do to promote recovery or what can be done in collaboration with occupational therapists to facilitate their community integration and social inclusion (Gibson, D'Amico, Jaffe, & Arbesman, 2011; Krupa, Fossey, Anthony, Brown, & Pitts, 2009). Occupation implies action and relates to the ordinary and extraordinary things people do as well as how they participate in, and experience daily life (Kuo, 2011; Townsend & Wilcock, 2004).

From an occupational therapy perspective, recovery-orientated services should consider the relationship between occupation, recovery and mental health (Kelly, Lamont, & Brunero, 2010) because it is currently underexplored, especially in resource-poor and socially disrupted communities. More needs to be known about the ways in which MHSUs engage with their lifeworld post discharge from residential-based programmes that aim to equip them with skills for daily community living.

### **1.4.7 Community integration and related services**

The development of appropriate services requires information about the ways in which MHSUs in historically disadvantaged communities conduct their lives through the ordinary everyday things that they do to promote their sense of community integration. A range of factors are likely to impact on the community integration of MHSUs. Additionally, limited occupational engagement opportunities may create conditions that make it difficult for MHSUs to successfully recover and re-integrate into their communities. Little is known about what community integration following a period of residential-based rehabilitation actually looks like for male MHSUs and how they deal with the barriers and opportunities awaiting them after discharge. Knowing more about their perspectives on community integration after admission to a residential-based rehabilitation service will assist public mental health services, including occupational therapy practice, to align their offerings with the needs of MHSUs.

### **1.5 Research problem**

Although step down/step up facilities were launched in the Western Cape in 2008 to offer residential-based rehabilitation, the impact of this service on the community integration of MHSUs has not yet been investigated. Despite the intention of Healthcare 2030 to give voice to service users' experiences of the health system (Western Cape Department of Health, 2014), no research has been done to date that reflects the views of male MHSUs on community integration after their participation in a residential-based rehabilitation programme in the Western Cape.

## **1.6 Research purpose**

This study will provide feedback on the contribution of residential-based rehabilitation services to the community integration of male MHSUs to the public mental health service sector in the Western Cape, South Africa.

## **1.7 Research question**

How does participation in a residential-based rehabilitation programme contribute to the community integration of men with serious mental disorders?

## **1.8 Research aim**

To describe the contribution of participation in a residential-based rehabilitation programme on the community integration of men with serious mental disorders.

## **1.9 Research objectives**

- To identify what men with serious mental disorders consider community integration to be.
- To describe the key elements within the residential-based rehabilitation programme that influenced their community integration.

## **1.10 Summary**

This chapter has provided a background to the research by introducing the topic of community integration of men with serious mental disorders who have participated in a residential-based rehabilitation programme. My personal interest as an occupational therapist involved in such a facility has been explained. Although this service was started in 2008, there is currently no research on the perspectives of male MHSUs who have participated in the programme. This chapter has argued that more needs to be known about the impact of the residential-based rehabilitation programme on the subsequent community integration of male MHSUs. This information will benefit health planners, service providers and service users because it can help to align MHSU needs with resource provision and allocation.

## **1.11 Overview of the research report**

The next chapter provides a review of the literature and considers service packages available for MHSUs in the Western Cape Province. Additionally community integration, recovery and the gendered consequences of occupational engagement, and their implications for mental health service delivery, are reviewed. Chapter three describes the research design and methodology. Chapter four introduces each of the five participants, providing insights into the contextual details of their health histories and social circumstances. The fifth chapter presents the findings including data as evidence to support the emerging qualitative theme and categories that answer the research question. The findings are discussed in chapter six and evidence from the literature is used to support the insights gained through the theme. The report concludes in chapter seven with recommendations from a theoretical basis for future research. I also discuss the limitations of the study and summarise the findings through concluding remarks.

## **CHAPTER 2: LITERATURE REVIEW**

### **2.1 Introduction**

The literature review explores the concepts underpinning mental health services and reviews the literature on the topic<sup>7</sup>. It goes on to describe mental health service transformation in the Western Cape, South Africa, including the introduction of residential-based rehabilitation services. Thereafter a discussion of the role of occupation in the recovery and community integration of MHSUs is presented. The chapter concludes with a gendered view of occupation.

### **2.2 Psychosocial rehabilitation, recovery and community integration of people with serious mental disorders**

#### **2.2.1 Definitions of health and psychiatric disability**

In the preamble to its constitution the World Health Organisation (WHO) defined health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (World Health Organization, 1946, p.100). Mental health has been defined as “a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully and is able to make a contribution to his or her community” (World Health Organization, 2001a). Well-being consists of physical, mental and social dimensions which allow people to gauge that they are happy, healthy and

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<sup>7</sup> See Appendix A for the literature search scope.

prosperous in their pursuit of a meaningful life (Nutbeam, 1998; Ann Allart Wilcock, 2006; World Health Organization, 2001b).

Mental health problems refer to minor distress, which can arise in people's lives due to factors within individuals, or from external causes. These may or may not require medical attention and all people have the potential to experience mental health problems at some time in their lives. Mental disorders refer to significant behavioural or psychological problems that causes distress, are medically diagnosable, impair the person's abilities to think, feel or relate to others and require specialist mental health services (Community Management ANTA Toolbox, 2013). When people with mental disorders become unable to perform their social roles and functions, they experience psychiatric disability due to their psychiatric disorder. Not all people with a mental disorder will experience psychiatric disabilities.

Within the literature there is debate around the use of the terms 'mental disorder' and 'psychiatric disability' (Community Management ANTA Toolbox, 2013; Siyabulela & Duncan, 2006; Stein et al., 2010). In this study the term 'severe mental disorder' is used interchangeably with 'psychiatric disability', since common mental disorders do not result in hospitalisation as often as is the case for severe mental disorders although their consequences might be equally disabling (Prince et al., 2007).

A systematic review conducted by Lund et al. (2011), found that social and economic conditions of poverty in LMICs countries are linked to common mental disorders. To include mental health in the development agenda requires recognition of the cyclical, complex and multidimensional interplay between poverty and mental disorders. Mental disorders contribute to the global burden of disease in their own right, as well as relative to other health conditions (Prince et al., 2007). Given their interactions with other health conditions they pose as risk factors for the development of communicable and non-communicable diseases, as well as accidental and non-accidental injuries. In light of this, mental health needs to be part of primary and secondary health care as well as be included in health and social policies

(Kohn, Saxena, Levav, & Saraceno, 2004; Prince et al., 2007; Whiteford et al., 2013).

### **2.2.2 Psychosocial rehabilitation and recovery**

Psychosocial rehabilitation (PSR) is an intervention directed at helping people with physical, psychosocial, intellectual and psychiatric disabilities to fulfil their desired roles in the environments of their choice. In their seminal work Farkas and Anthony (1991, p.7) describe environments as living, working, learning and socialising spaces. PSR refers to the services and technologies offered to persons with disabilities so that they can adapt to their world, whereas recovery refers to the lived experience involved in overcoming the challenges posed by having a disability (Deegan, 1988, 1995; Farkas, 2008; Slade, 2010b). The seven technologies used by professionals in PSR are:

- Readiness assessment
- Setting an overall rehabilitation goal
- Functional assessment
- Resource assessment
- Direct skills teaching
- Programme skills use
- Resource and social mapping

Deegan (1988) differentiates between rehabilitation and recovery by saying that mental health service users do not get rehabilitated by health professionals, but rather they regain a sense of value and personal purpose as active participants in their own recovery. New developments in the field call upon professionals to draw on clients' assets and lived experiences when they embark on their recovery journeys (Corring & Cook, 2006; Kramers-Olen, 2014).

Recovery has been at the centre of debate amongst mental health consumers, service providers and stakeholder groups in terms of what recovery means and how different health systems<sup>8</sup> can help or hinder the recovery journey (Farkas, 2007). In his seminal work Anthony (1993, p.527) defined recovery as:

*“A deeply personal, unique process of changing one’s attitude, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful and contributing life even within the limitations caused by illness. Recovery involves the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness.”*

Slade (2009) distinguishes between clinical recovery and personal recovery. Clinical recovery is profession-led and invariant across individuals. Its focus is on symptom alleviation and cure of the illness. It is seen as a subset of personal recovery. Personal recovery is a MHSUs’ understanding of recovery, which looks beyond clinical recovery towards rebuilding a meaningful life (Slade, 2009). This definition of recovery recognises that while individuals may still live with distressing symptoms, they can reclaim their lives through taking up valued social roles and developing a positive self-identity (Tew et al., 2011). The principles of PSR and recovery, along with the strategies of qualitative research, are compatible with the values, beliefs and language of occupational therapy (Corring & Cook, 2006; Kelly et al., 2010; Krupa et al., 2009). A recovery-focused service would acknowledge that while some service users benefit from traditional practices, others may be harmed by the mental health service (Slade, 2010a).

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<sup>8</sup> Health systems refer to the different people, institutions and resources that deliver services in order to meet the needs of the target population. Health systems contribute to the social determinants of health and are needed to improve health status and address health inequalities (Ataguba et al., 2011).

Definitions of recovery address concepts such as self-identity and hope (Wisdom, Saedi, Weis, & Green, 2008). A review of the literature connecting social factors and recovery was conducted by Tew et al. (2011). Their findings suggest that since recovery entails personal change and social engagement, it can only be promoted if service providers work with individuals, their families and communities at large. They found that the key societal factors enabling recovery are relationships and the social aspects of mental health. The social factors which emerged, include overcoming discrimination and stigma, connectedness through interpersonal relationships, social capital, social inclusion, empowerment and having control over one's life.

One way to overcome stigma and discrimination is by improving the mental health literacy of the public and health professionals. The term mental health literacy was coined by Jorm, Korten and Jacomb (1997). It refers to knowledge, attitudes and practices, which aid the recognition, management or prevention of mental disorders. This includes the ability to recognize psychological distress; seek mental health information; awareness and cause of risk factors and gaining access to professional help (Jorm, Korten, Jacomb, Christensen, & Henderson, 1999; Jorm et al., 1997; Kelly, Jorm, & Wright, 2007). All health professionals need to understand and have a positive attitude towards people with mental disorders if they are to provide effective support (McCann & Clark, 2010; McCann, Lu, & Berryman, 2009). Additionally improving mental health literacy on a community level will influence the social factors enabling recovery (Coles, Coleman, & Heimberg, 2008; Jorm, 2000).

In a qualitative study conducted by Kelly et al. (2010), the collective narrative of recovery emerged as an occupational journey involving responsibility, choice, hope, empowerment and the search for personal meaning. Participants' re-engagement with life was promoted through occupations which fostered mutual support, friendships, community participation and the acquisition of coping skills (Kelly et al., 2010; Krupa et al., 2009). In essence, mental health recovery emerges from narratives of MHSUs through an ongoing, cyclical and idiosyncratic journey which includes dimensions of

hope, empowerment, knowledge and life satisfaction (Farkas, 2007, 2008; Slade, 2009), the goal of which is not to become more normal but rather to become more human (Deegan, 1995).

Community integration is a multidimensional construct. According to Linden, Crothers, O'Neil and McCann (2005), community integration should be the aim of all forms of interventions, including recovery and PSR, as it considers the barriers faced by disadvantaged individuals as they try to participate fully in society. There are various definitions of community integration but common features include social relationships, activities of daily living and the meaningful use of time (De Wolf, Lane-Brown, Tate, Middleton, & Cameron, 2010).

McColl, Davies, Carlson and Johnston (2006; 1998) identified four elements, which contribute to community integration, namely: assimilation (conformity, orientation, acceptance); social support (relationships); occupation (leisure, productivity); and independent living (satisfaction with living arrangements). Findings from a qualitative study on the community integration of young adults conducted by (Jivanjee, Kruzich, & Gordon, 2008) and supported by the Tew et al. study (2011), found that while participants had many goals which they aspired to, the stigmatising attitudes present in interpersonal interactions, structural discrimination, public images of mental health and access to social roles diminished their experiences of being successfully integrated into their communities. This is supported by the findings of the as discussed earlier in connection with social factors which promote or impede recovery.

## **2.3 Mental health service transformation in the Western Cape, South Africa**

### **2.3.1 Mental health service history**

In the Western Cape Province there are three specialist psychiatric hospitals and an additional service dedicated to adults with intellectual disabilities. Together these comprise the Associated Psychiatric Hospitals (APH) group. The first specialist psychiatric hospital designated for white MHSUs was opened in 1891. It was geographically located so as to be accessible to their families and friends (Gillis et al., 2012). The hospital only opened its doors to people of all races 100 years later, in 1991.

Policy changes at that time, along with the advent of democracy in 1994, saw this tertiary hospital embark on a process of deinstitutionalisation and devolution of mental health services to primary and secondary levels of health care. However, rapid deinstitutionalisation of mental health service users occurred without the simultaneous development of accessible community-based services. This has resulted in 'revolving-door'<sup>9</sup> patterns of care, high levels of homelessness amongst MHSUs and increasing numbers of mentally ill people in prisons (Department of Health, 2013). While South African mental health legislation and policies seek to redress the legacies of apartheid, public mental health services remain inaccessible, underdeveloped, under-resourced, fragmented and inequitably distributed (Ritsuko Kakuma et al., 2010; Kleintjes et al., 2013; Kleintjes & Lund, 2010; Myer et al., 2008).

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<sup>9</sup> Refers to the continuous cycle of admission, discharge and readmission that MHSUs find themselves in.

### **2.3.2 Mental health service policy**

In 2013 the National Mental Health policy framework and strategic plan 2013-2020 was launched (Department of Health, 2013). The intention of the framework is to identify key activities that will transform mental health services in South Africa through the promotion of mental health and reduction of untreated mental disorders (Department of Health, 2013, p.3)

In March 2014, the Western Cape Department of Health launched its draft framework for dialogue entitled, *Healthcare 2030: The Road to Wellness* (Western Cape Department of Health, 2014) in response to the National policy. This is a value-based approach to mental health services where patient experience and well-being is at the core, indicating a conscious move to a “whole society approach to wellness” (Botha in Western Cape Department of Health, 2014, p.x). Healthcare 2030 is seen as a continuation of the comprehensive service plan with its “*vision narrative*” to develop a service delivery platform that provides client-centred quality of care (Western Cape Department of Health, 2011). Against this backdrop, research is indicated that captures the perspectives of service users on the benefits of a residential-based rehabilitation programme in facilitating their recovery and community integration after discharge.

### **2.3.3 Mental health services in the Western Cape**

A study conducted by Kakuma et al. (2010) looked at public mental health service providers within South Africa. Their study included non-profit organisations (NPO) providing mental health services. In the Western Cape the following services were identified in the study:

- 455 outpatient clinics (general health clinics where mental health statistics are not monitored)

- Two-day treatment facilities (run by an NPO, no information on length or treatment data was found)
- Six psychiatric inpatient units in general hospitals (offers 72-hour assessment as per the MHCA)
- Nine community residential facilities (in the NPO sector 41% are female while the Department of Health does not keep gender specific statistics), and
- Three mental hospitals (1% of beds are dedicated to children and adolescents; outpatient services are integrated into the hospital) (Kakuma et al., 2010, p.398).

While South African policy advocates for community-based mental health services, the implementation of this across the country is weak.

#### **2.3.4 Mental health service models in the Western Cape**

Mental health service delivery models are needed to address the range of psychosocial needs of people with mental disorders, including their rights as citizens to social inclusion and participation in community life. One response to meet the demand for continuity of care and access to mental health rehabilitation opportunities in the Western Cape, was the launch by the APH of two step down/step up residential-based rehabilitation programmes in 2008 (Kleintjes & Lund, 2010; Myer et al., 2008).

While admission to a psychiatric hospital is classified as involuntary, or assisted on the basis of risk of self-harm or harm to others (South African Government, 2002), admission to the Gateway programme is voluntary. The vision of the service is to provide “alternative, residential-based recovery and rehabilitation services for people with severe mental disorders” (Associated Psychiatric Hospitals, 2008, p.1). Its overall function is to provide specialised inpatient rehabilitation through relieving pressure on the acute admission system and complementing the services of the Assertive Community

Treatment (ACT) team attached to the psychiatric hospital (Associated Psychiatric Hospital, 2008).

The ACT team deals with potential high frequency service users. ACT is a service delivery model aimed at providing continuous care, treatment and rehabilitation to MHSUs who are seen frequently in the service system (Krupa, McLean, Eastabrook, Bonham, & Baksh, 2003). MHSUs attend the residential programme for three to nine months after which they are discharged to home. They are referred to the community health centre (CHC) closest to where they live for medication collection and follow-up. Alternatively the ACT team sees them indefinitely if they are first time admissions, or are found to be treatment-resistant 'revolving-door' admissions.

The multidisciplinary ACT team is an ambulatory service started in 2006 as an extension of the APH service. The team takes a case management approach with the aim of reducing the treatment-resistant 'revolving-door' type of admissions of those with severe mental illness (Kleintjes et al., 2008). MHSUs who miss appointments with their case manager, are actively followed up and offered support or assistance so that no one gets "lost" in the system (Q.Cossie, personal communication, 9 December 2014). The ACT team attached to the step down/step up facility in this study comprises a psychiatrist, psychiatric nurse, social worker and medical officer.

### **2.3.5 Effectiveness of care for MHSUs**

A study of daily time use of MHSUs served by an ACT team conducted by Krupa et al. (2003) found that while the team supported medication adherence and reduced hospitalisation, their role in the promotion of well-being and quality of life is less known. They report that within the multidisciplinary ACT team occupational therapy services can contribute a specialist rehabilitation role. It should be noted that the ACT team affiliated to

the psychiatric service in this study does not have an occupational therapist attached to it.

A systematic review conducted by Gibson et al. (2011) indicated that more research in the areas of recovery is needed since direct evidence of effective interventions is limited. When looking for evidence they suggest considering the components of occupational therapy interventions for recovery. The areas they included in their review were: life skills training, social skills training in the areas of work, social participation and individual supported employment opportunities. Gathering evidence about what MHSUs perceive the key elements of a residential-based rehabilitation service to be could advance the development of relevant programmes for PHC and community integration.

According to Pettican and Bryant (2007), community-based services must consider the autonomy of MHSUs from an occupation focused point of view through enabling opportunities, balancing occupations and taking into account MHSUs' need for belonging so that everyday life can be meaningful and purposeful. They argue that transitory staff and an integrated health service fail to support MHSUs' need for a designated care worker with whom they can build a relationship with over time (Pettican & Bryant, 2007). Current models of service are driven by the professional capacity of case managers and do not consider MHSUs' self-identified needs

A randomised trial conducted by Fenton, Hoch, Herrell, Mosher and Dixon (2002) looked at the 6-month cost and cost-effectiveness of hospital versus residential crisis care for MHSUs. They concluded that residential crisis programmes, which required voluntary admission, offered a cost-effective way of providing acute care for MHSUs as an alternative to psychiatric inpatient treatment. In resource-scarce areas a combination of hospital, community-based residential crisis and community support services are recommended. In the Western Cape the step down/step up programme can be viewed as a residential-based rehabilitation service following an inpatient crisis psychiatric admission.

## **2.4 Occupation: its role in recovery and community integration**

Humans engage in different occupations across their life span, as various opportunities and needs arise. Understanding recovery from mental illness through an occupational lens is crucial, given the current focus on medical stabilisation and alleviation of symptoms as the dominant measure of recovery in acute mental health services.

Wilcock (1999, 2006, p.xiv) defines occupations as “all the things that people need, want or have to do across the sleep-wake continuum,” and a synthesis of “doing, being and becoming”. She advocates for an occupation-based perspective on health and well-being through understanding how people spend their time and energy engaging in occupations.

### **2.4.1 Categorisation of occupations**

Occupations have historically been categorised as either self-care, leisure or productivity (Krupa et al., 2009). This categorisation is reductionist according to Hammell (2004, 2010) because it does not reflect the complexity of occupations, or the influence of social, political and economic factors on occupational engagement. People are not always able to access their right to participate in occupations as autonomous agents. Understanding the tacit influence of social, political, economic and other contextual factors on occupational engagement, has health and human rights implications, all of which impact on a person’s experience of community integration (Hammell, 2007; 2010, 2011).

A transactional view of occupation was proposed by Cutchin et al. (2008). Herewith follows their definition of occupation:

A type of relational action through which habit, context, and creativity are coordinated toward a provisional yet particular meaningful outcome that

is always in process; the type of occupation is defined by the particular combination of habit, context, creativity, and provisional outcome. (p.164)

The transactions between the person, environment and occupations engaged in, thus promote recovery and improve mental health irrespective of the presence of mental disorder. Adopting a broader occupational lens with the view that occupations are transactional in nature, and are experienced by the individual in society and society on the individual (Kuo, 2011), will also help with fully appreciating what community integration entails.

#### **2.4.2 Occupational choice and engagement**

Understanding occupation provides researchers with insights as to what motivates people to do what they want, need and choose to do, and how these influence their mental health (Farnworth & Muñoz, 2009). Hammell (2010) suggests that occupational therapists have the capacity to provide opportunities for people to describe occupations related to their perspectives and experiences of past, present and potential engagement, and to explore the influence of these occupations on their health and well-being. As highlighted in Swartz (2002), people improvise on their occupations when they bargain and negotiate the rules to reflect their interest, desire or self-preservation in society. One needs to consider the impact of collective pressure, group identity and institutional culture in understanding occupational participation within institutional and community settings. It is suggested that occupational therapists could be forerunners in helping society to understand occupations as complex, multidimensional phenomena engaged in by social collectives (Fogelberg & Frauwirth, 2010). Little is known about the social collective experiences of MHSUs during their six to nine month stay in a step down/step up rehabilitation facility and how it prepares them for community integration.

Humans are occupational beings who devote time and energy to exercising choice at individual, organisational, political, social and economic levels.

Occupational therapists should foster opportunities and possibilities to facilitate occupational choices (Galvaan, 2015) which speak to diverse values, social relationships, interdependence, reciprocity, connections and a sense of belonging (Hammell, 2010). Participation in everyday occupations is a complex issue influenced by the environment, the family (or social system)<sup>10</sup> and the person (Law, 2002). It can thus be argued that occupation is a determinant of health and well-being since engagement in occupations is potentially transformative (Krupa et al., 2009) and disruptive (Pettican & Bryant, 2007), creating personal and social identities through which people connect to their communities. Mental health disorders and the social determinants of mental health can intersect in causing occupational disruptions. Krupa et al. (2009) argue that the rehabilitation focus of occupational therapy is to enable occupations after disruptions. The challenge for occupational therapists adopting an occupation-based approach is to pay attention to how they offer occupational engagement opportunities so as to positively influence “ends in view<sup>11</sup>” experiences that matter.

## **2.5 Gender and mental health service users**

### **2.5.1 Men and mental disorders**

Gender and development studies tend to exclude an exploration of men’s gender experience, or when they are considered they are viewed as

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<sup>10</sup> The concept of ‘family’ is a Westernised notion of the nuclear social unit. In the African context, people are more likely to be assimilated into a ‘household’ consisting of parents, grandparents, aunts, uncles, cousins and distant relatives (Banda, 2014). Due to the death of parents as a result of HIV/AIDS, a significant proportion of the population under the age of 18 are not living in ‘families’ but reside in government and NPO care facilities (Blas & Kurup, 2010).

<sup>11</sup> Our goals or ‘ends’ are guided creatively and imaginatively ‘in view’ of our future possibilities (Cutchin et al., 2008).

obstacles to women's development (Cleaver, 2002, p.1). However, the needs of men are equally pressing. Men as well as women have the right to freedom from poverty and oppression; both are disadvantaged by socio-economic policies; labour division and social practices impact on men's opportunities for education and work; men suffer more ill-health than women; and mental health problems amongst men make them more prone than women to attempting suicide (Cleaver, 2002, p.2). Whiteford et al. (2013) found that 80% of suicides were attributable to mental and substance use disorders amongst men.

A study conducted by Gunter, Philibert and Hollenbeck (2009), where 65% of the participants were males in community-based correctional services, found that mental health disorders were more common than other medical conditions amongst this population. While some men are able to resist aspects of hegemonic masculinity, others felt oppressed by their prescribed roles and this might contribute to the development of mental health difficulties (Tew et al., 2011). In the Gunter et al. study (2009), substance use disorders were the most commonly occurring psychiatric disorder amongst men. Gunter et al. (2009) advocate the concurrent evaluation and treatment of co-occurring medical and psychiatric disorders in men and women, using community-based correctional services so as to understand the different gender based needs.

### **2.5.2 The occupational engagement of men**

A focus on the occupational engagement of male MHSUs allows one to consider the way in which men might participate in life situations according to their perceptions of what society expects of them (Polatajko et al., 2007). Efforts to impact the occupational engagement of men require attention to interventions focusing on the structural dimensions of men's lives, such as education and opportunities for employment and development (Jewkes et al., 2009).

Developmentally, men are expected to contribute productively to their household and community. However, the changes in household composition, with more female-headed households, impacts on male youth and is seen through antisocial behaviour and violence (Cleaver, 2002). Involuntary unemployment rates are high in South Africa (Davies & Thurlow, 2009; Statistics South Africa, 2012), and this is particularly relevant on the Cape Flats. While joining a gang could be labelled as antisocial behaviour, on the Cape Flats it can also be viewed as adaptive behaviour because of the context within which youth find themselves, and because of the opportunities for informal employment that gang membership offers. Gang membership also offers attractive role models and camaraderie to male youth as well as opportunities to display courage (Coovadia et al., 2009; Jewkes et al., 2009; Standing, 2003). The segregation policies of apartheid rendered male aspirations of having and providing for a family unattainable for most urban and rural black and coloured men. The apartheid legacy of gangsterism continues to thrive across the Cape Flats to this day (Pelser, 2008).

Since social interactions influence the past, present and future selves of individuals, their identities can change and are influenced by the social environment (Slade, 2009). Having a mental illness threatens the identity and sense of self that MHSUs might have, and exploring these shifting identities in the light of what might help or hinder their community integration, could contribute to the reconstruction of a meaningful identity and sense of self (Carless & Douglas, 2008). Stigmatising attitudes towards mental illness make community participation challenging for men with serious mental disorders (Jivanjee et al., 2008).

Understanding the perspectives of males on the processes of community integration would add value by sensitising clinicians to gender as a guiding factor in designing the content of rehabilitation programmes. Additionally, a gendered view on occupational possibilities would consider which occupations are ideal, expected or appropriate for male MHSUs and which occupations exclude them. Through this, occupational therapy can play a role in helping mental health services to reorganise the content of their

programmes so that the links between recovery, occupations and mental health can be developed (Kelly et al., 2010).

## **2.6 Summary**

The literature review has argued that research in mental health service transformation is still developing. An exploration of the key concepts underpinning mental health services was discussed. In order to contribute to the service transformation in the Western Cape, residential-based rehabilitation services were introduced along with an explanation of the service. The chapter concludes with the proposition that given the socio-economic and political factors which have shaped South Africa, a gendered understanding of occupational engagement is needed. The absence of MHSUs' voices in planning such services is evident in the literature and to this end I have focused this study on the perspectives of male MHSUs.

## **CHAPTER 3: RESEARCH DESIGN**

### **3.1 Introduction**

This chapter describes the theoretical underpinnings and methodology employed in the study. Aligned to the tenets of qualitative case study design, this study respects the multiple realities from which data emerged and the complexities in representing this holistically (Creswell, 2007, p.37). It includes sections on the research methods utilised and the process followed for generating, managing, analysing and interpreting the data. Four sources of data generation were used. Data analysis followed an inductive process with a focus on participants' sense of community integration after being in a residential-based rehabilitation facility. As I was the data collector in an emergent research process, the chapter is written in the first person.

### **3.2 Philosophical standpoint**

This study is informed by the epistemology of constructivism, a worldview that is suited to individuals seeking to understand the historical and cultural world in which they live and work (Creswell, 2007). Constructivism comprises five principles: activity, order, self, social-symbolic processes and lifespan development (Mahoney & Granvold, 2005, p.74). Activity refers to humans as being active participants in the process of experiencing their own lives, in this instance, experiencing life with a severe mental disorder. The second principle recognises the human need for organising and responding to order in their world, often through habits and the emotions central to active engagement in life. Constructivism views the self as a fluid process not as an isolated entity. Humans, in sickness and in health, thus order their world by organising themselves from within, as well as in relation to others. As social

creatures, humans reflect the principle of social-symbolic relatedness. The fifth principle of lifespan development offers an understanding of the developmental process through which humans reorganise themselves in the face of life challenges during each age and stage of life (Mahoney & Granvold, 2005, p.76).

I considered constructivism to be a suitable philosophical framework for answering the research question because it sees knowledge as being constructed through individual perception and social understanding (Savin-Baden & Major, 2013). If mental disorder is constructed as a trigger for development and personal growth, then MHSUs are in the best position to reflect on the learning opportunities provided by the step down/step up programme and on their subsequent community integration. Since constructivism does not necessarily seek to reflect external reality, it provides a suitable philosophical framework for understanding how MHSUs construct (make sense of) community integration. Aligned with the research focus, constructivism allowed the subjectivities of the illness experience to be voiced while exploring the implications of the clinical model (step down/step up rehabilitation programme) for recovery-orientated community integration. My intention with adopting a constructivist position was to interpret the perspectives of MHSUs on their interactions with others via the health service with due consideration of cultural, social and historical norms, while remaining cognisant of how my own background shapes the constructions of reality that are made.

### **3.3 Tradition of inquiry**

A qualitative research approach and case study methodology were selected as the traditions of inquiry for this study, with the case of interest being MHSUs' particular ways of operationalising community integration after participation in a step down/step up rehabilitation programme. Case studies are useful for explaining, describing or exploring events that will assist in

understanding connections between policy initiatives and service developments (Creswell, 2007; Lincoln & Guba, 1985; Yin, 2009). Case studies may be instrumental, intrinsic, or collective (Stake, 2006). An instrumental case study uses a particular case to gain general insight and appreciation of an issue while an intrinsic case study allows the researcher to develop a deeper understanding of a unique phenomenon. A collective case study is the study of a number of cases in order to generate extensive knowledge of a particular issue (Stake, 2006).

Instrumental case study was selected as the tradition of inquiry for this study because it provided the most suitable way of gaining a general understanding of how an intervention is implemented (a step down/step up rehabilitation programme) and received by its intended audience (male MHSUs). Instrumental case studies allow researchers to look beyond the borders of the case itself, and to develop insight into and provide opportunities to learn about a particular issue, area of concern or marginalised population (Stake, 2006, p.8). Instrumentality would take account of the contextual issues in both the step down/step up programme and the community into which MHSUs are integrated. The findings may lead to and inform additional research on the community integration of male MHSUs and other interventions which can support their transitions between hospitalisation and re-entry into daily life spaces.

### **3.4 Research context**

This study is located in the Western Cape, one of South Africa's nine provinces. Within the Western Cape there are six municipalities (local government), which are divided into five rural districts and one metropolitan district as reflected in Figure 3.1, which follows.



**Figure 3.1: Western Cape Province**

(City of Cape Town, 2013)

This study drew on participants from the metropolitan district of the City of Cape Town (referred to on the map as Metro Central). Key statistics (Statistics South Africa, 2012) for this district is reflected in Table 1 below.

**Table 3.1: City of Cape Town**

Area size	2 461 km <sup>2</sup>
Total population	3,740,026
Young (0-14)	24,8%
Working age (15-64)	69,6%
Elderly (65+)	5,5%
Growth rate	2,57% (2001-2011)
Population density	1530 persons/km <sup>2</sup>
Dependency ratio	43,6%
Unemployment rate	23,9%
Number of households	1, 068, 573
Formal dwellings	78,4%
Household income below poverty line (ZAR3600 per month)	35,7%

(Statistics South Africa, 2012)

The Cape Flats<sup>12</sup> is included in the City of Cape Town metropolitan district and falls within the Gateway<sup>13</sup> and Horizon<sup>14</sup> hospital catchment area. The discriminatory Group Areas Act of 1950 (Arise Cape Town, 2011) sought to separate racial groups geographically and restricted people in terms of property ownership, occupancy and trade, resulting in economic repercussions for the people who were relocated. Low-cost, densely populated apartments and three-storey hostel type housing was constructed with limited attention to the creation of recreational, sport, play, commercial and other social spaces. Urban segregation between coloured and black people was legally sanctioned in Cape Town through the removal of black people from the inner city to township<sup>15</sup> areas on the fringes of urban areas. According to Swanson (1977 in Steinberg, 2011) this segregation was imposed under the guise that for health reasons separating black and coloured people would decrease the spread of bubonic plague. In post-apartheid South Africa residents across the Cape Flats continue to be marginalised as high levels of crime, violence, gangsterism, substance abuse, poverty and unemployment persist (du Preez, 2013; Steinberg, 2011).

### **3.5 Research sites**

#### **3.5.1 Gateway residential-based rehabilitation facility**

Gateway is part of the teaching and research platform linked to a local university and tertiary hospital within the Cape Town Metropole. It was

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<sup>12</sup> See footnote 3 for explanation of Cape Flats.

<sup>13</sup> See footnote 2.

<sup>14</sup> Pseudonym used for the referring specialist psychiatric hospital in this study.

<sup>15</sup> Residential suburbs with formal and informal housing designated for black people in the apartheid era.

selected as the study site of interest because it is a relatively new service started in 2008. It provided a bounded case of a programme geared towards facilitating the community integration of male MHSU's residing in the catchment area serviced by Horizon hospital. Gateway is a 40-bedded unit where the general ratio of male to female residents is 32:8<sup>16</sup>. The average length of stay ranges from three to nine months and participation is on a voluntary, inpatient basis. MHSUs must have a diagnosis of serious mental disorder. These include schizophrenia, schizoaffective disorder, bipolar affective disorder and first episode psychosis. MHSUs with other diagnoses are considered if they are assessed to be well enough (i.e. the acuity of active psychiatric symptomatology has subsided enough for the individual to be understood and able to participate in the programme) (Associated Psychiatric Hospital, 2008).

### **3.5.2 Referral pathways to and from Gateway**

The Gateway service is described as step down/step up (intermediary from tertiary level care or from PHC). This distinction of the function of the programme refers to the referral path and type of services available to MHSUs. The goal of the step down/step up programme is twofold.

Firstly, it is used to stabilise MHSUs during the sub-acute phase of their recovery when they can no longer be accommodated in tertiary level care but they still require a longer admission in a structured environment with clinical supervision. Referral to the programme occurs via specialist psychiatric teams based in the specialist psychiatric hospital (Horizon). Thereafter the medical officer attached to the ACT team screens all cases referred for potential admission to the step down/step up programme. Voluntary admission is recommended when step down containment and stabilisation

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<sup>16</sup> More men are referred to the programme than women. The prevalence of serious mental disorders are higher in men whereas more women are diagnosed with depression and anxiety disorders (Hamad et al., 2008). At the time that the study was concluded Gateway was an all-male facility.

from acute hospital to sub-acute care or intermediate care is indicated for the individual concerned (Associated Psychiatric Hospital, 2008).

Secondly, referrals can be made to the step down/step up programme from the PHC level as a preventative measure against relapse and acute admission to tertiary level care. In this case step up care is indicated when MHSUs who are at risk of a breakdown are referred to the programme via the local community mental health nurse or medical officer. This is done to prevent an acute, crisis admission to the psychiatric hospital. This step up service is not emphasised in the documents that were reviewed for this study and none of the study participants had been admitted to Gateway via this route. All MHSUs are seen at the Horizon hospital Outpatient Department (OPD) while they are in Gateway. During the last month of their stay at Gateway they are referred to the local CHC closest to where they live to collect their psychotropic medication.

### **3.5.3 Identification of research site**

This study was initially going to focus on the suburb of Heideveld, 20km away from the city centre because of the high admission rate of MHSUs living there. As the PHC service is an integrated one, MHSUs who have completed the Gateway programme are not referred directly to the mental health nurse based at Heideveld CHC. There is thus no direct liaison between the mental health nurse at Heideveld CHC and Gateway as to who is returning to the community, and consequently there is no database reflecting who attended Gateway or the duration of their stay. Because of the vague referral pathway and client record system between Gateway and Heideveld CHC, I decided to broaden my focus area to cover the Gateway and Horizon hospital catchment area within the City of Cape Town metropolitan district.

### **3.5.4 Gateway programme**

The Gateway step down/step up programme is group based and structured to include topics and activities such as psycho-education and treatment adherence, development of self-care and daily living skills and exploration of creativity as well as social and community integration skills (Associated Psychiatric Hospitals, 2008a). The team comprises nurses, home based carers, an occupational therapist and a social worker. All staff members are involved in delivering the programme and are supervised by the facility manager who is a social worker by profession.

### **3.5.5 Gaining entry**

I obtained ethical approval to conduct my study within the Horizon hospital catchment area. The proposal was reviewed and approved by the University of Cape Town, Faculty of Health Sciences Human Research Ethics Committee (HREC REF 582/2013) (Appendix B) as well as the Western Cape Department of Health Impact Assessment Unit (RP156/2013) (Appendix C). After ethical approval was granted I contacted the mental health nurses at Horizon hospital and Gateway.

The principal mental health nurse at Gateway was the research site gatekeeper<sup>17</sup>. She assisted me in identifying 20 male participants who potentially met the sampling criteria (see below). Thereafter I approached the Horizon hospital OPD nurse who helped me to locate the folders of the identified MHSUs. I scrutinised the files and identified 12 participants who met the inclusion criteria. None of them had clinic appointments reflected on

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<sup>17</sup> Gatekeepers are individuals in authority positions whose approval and support is central for access to participants and entry into the research context (Kelly, 2006b).

the database or in the folder and I undertook telephonic contact with each one individually. During the telephonic interview I explained the study to them. I also negotiated interview times at a location of their choice for the five participants who agreed to meet me. The reasons for non-agreement ranged from being readmitted, not being interested in participating or their family not wanting them to participate. Since the participants were deemed a vulnerable group by virtue of their psychiatric disability, I did not persist when they declined participation because doing so may have been construed as coercion and a breach of ethical research conduct (Rule & John, 2011).

### **3.6 Study population and sampling**

This study was bounded by place (Cape Town Metrople), context (Gateway step down/step up facility), persons (male MHSUs) and time (at least one year post residential-based exposure). The study population included all male MHSUs who had been discharged from the Gateway programme at least one year prior to the commencement of the study. Given the protracted recovery associated with severe mental illness (Farkas, 2007; Slade, 2010a), a year was deemed a suitable time period to experience community integration after completing the Gateway programme. Purposeful maximal variation sampling was used in this study (Creswell, 2007, p.74) to ensure that a range of perspectives was documented. Maximal variation sampling (Flick, 2009) allowed me to select cases that potentially would reflect diverse experiences of community integration. Five male participants who met the variation criteria agreed to participate in this study (Creswell, 2007). Rule & John (2011) support the selection of a few cases to aid in understanding the multiple realities of the issue in question.

### 3.6.1 Inclusion criteria

The study considered the inclusion of MHSUs who:

- had been at Gateway at least one year prior to the study. The duration of a year or more was indicated because sufficient time is needed for a person to settle into routine patterns of living following a hospital admission.
- are males between the ages of 18-55 years. This age band was selected as individuals in this group can give informed consent and are expected to contribute productively to society.
- speak English or Afrikaans as their first or second language. This was due to the time and financial constraints in the use of translators for other languages which I do not speak.
- have a primary diagnosis of a serious mental disorder.
- were apsychotic at the time of the initial contact in order to give informed consent.<sup>18</sup>
- were willing to be interviewed more than once in the research process. The first interview created rapport and the second interview allowed space for clarifying issues raised in the first.

Maximum variation was plotted using the following indicators:

- Age: consideration was given to age of onset of mental illness and chronological age (Patel et al., 2007; Whiteford et al., 2013).
- Race: the racial based legacy of apartheid still resonates in the kind of life people are able to live (Coovadia et al., 2009; Erasmus, 2001; Mooney & McIntyre, 2008).
- Diagnosis: different forms of mental disorder impact on functioning in different ways (Chisholm et al., 2007; Davidson & Roe, 2007; Wittchen et al., 2011).

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<sup>18</sup> I conducted a brief mental state examination during the initial invitation conversation. I asked questions related to orientation to time, place and person in order to assess this.

- Time since discharge from Gateway: one year post discharge from Gateway was considered an adequate time frame to allow participants to reflect on their step down/step up experience and their sense of community integration (National Alliance on Mental Illness (NAMI), 2009).
- Residential circumstances: where MHSUs live and whom they live with influences their mental health and well-being (Erasmus, 2001; Townley et al., 2009; Yanos, 2007).
- Employment history: consideration was given to employment in the formal and informal sector as well as barriers to participation and the high unemployment rate in the country (Kleintjes et al., 2013; Statistics South Africa, 2012).
- Substance abuse history: given the prevalence of dual diagnosis (co-occurring substance abuse and mental disorders) participants with a history of substance abuse were included in the study (Patel et al., 2007; Whiteford et al., 2013).
- Gang-related activity history: the high incidence of gang related activities and its impact on crime was considered in the study (Standing, 2003).
- Number of previous admissions: participants varied in terms of how long they had been living with a mental illness and their number of prior hospital admissions (Slade, 2009).

### **3.6.2 Exclusion criteria**

- Participants who do not meet the above criteria were excluded.

The inclusion and exclusion criteria were discussed with the mental health nurse at Gateway as she assisted with sampling. She also knew all the participants as she had been there since the inception of the programme in 2008.

### 3.6.3 Participant profiles

A summary of demographic details related to the five participants is represented in Table 3.2.

**Table 3.2: List of participants**

<b>Pseudonym<sup>19</sup></b>	<b>Age</b>	<b>Race</b>	<b>Residential area</b>	<b>Year<sup>20</sup> of admission to Gateway</b>	<b>Diagnosis</b>
<b>Mikaeel</b>	55	Coloured	Claremont (designated white area during apartheid)	2012	Schizophrenia
<b>Bolo</b>	29	Coloured	Heideveld (Cape Flats)	2010	Schizophrenia
<b>Gershwin</b>	39	Coloured	Retreat (Cape Flats)	2011	Bipolar Affective Disorder
<b>Emmanuel</b>	29	Black	Khayelitsha (Township)	2012	Schizophrenia
<b>Dan</b>	27	White	Mowbray (designated white area during apartheid)	2011	Schizo- affective Disorder

### 3.6.4 Informed consent

Each participant was presented with a study information sheet and was asked to complete a consent form agreeing to participate in the study (see Appendix D and E). Participants were all between the ages of 18- 55 years, and as such were able to give consent. The voluntary nature of their

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<sup>19</sup> Pseudonym of participants own choosing is used to ensure confidentiality.

<sup>20</sup> The year of admission and not the dates of admission and discharge are used to ensure confidentiality.

participation and their contribution to helping service providers understand their experience was explained to them at the start of the study. They were informed of the aim of the study, data collection methods and mechanisms to ensure their anonymity, privacy and confidentiality. They were told of potential benefits and risks of participation, the voluntary nature of their participation and what was required of them. All costs related to the research were my responsibility and participants were not inconvenienced in any way.

I explained to participants that by conducting this study, I have a responsibility to share the findings with stakeholders in higher education, health sector and mental health advocacy groups. I arranged to meet each participant at a venue of his choice. Venues included two local libraries, one occupational therapy department and two group homes. These venues were all quiet and distraction-free and lent themselves to audio recording (Creswell, 2007). After I introduced myself, the consent form was discussed and completed and I explained the purpose of the dictaphone in capturing what was said. I also explained how I would be using the information. I then started the recording and proceeded with the interview. Participants were free to signal their need for a break and the interviews generally lasted between 45 and 60 minutes.

### **3.7 Data generation methods**

Case study research, allowed me to gain insight into the case of community integration through the convergence of findings from various data sources (Baxter & Jack, 2008). Case study methodology allows for multiple methods of data collection such as interviews, artefacts, audio-visual materials, observations, documents and reports (Creswell, 2007). The process of collecting data from multiple sources is known as data source triangulation (Stake, 2006). Four methods were used to strengthen triangulation: interviews, resource mapping, observation and journaling.

### 3.7.1 Interviews

Flexible one-on-one conversations in the form of semi structured interviews of approximately 45 minutes were conducted with each participant using an interview schedule (see Appendix F). The design of the interview schedule was based on the research objectives and guided by the definition of community integration by McColl, Davies, Carlson and Johnston (2006). As suggested by Creswell (2007), a pilot interview was conducted with one male MHSU residing in a group home. This interview was used to help me refine the interview schedule and data collection process. The interview schedule was used as a guideline and I was flexible in my adherence to it, preferring to allow time for participants to respond freely (with due consideration to their fluctuating mental state) in order for their views to unfold.

The initial interview was used to build rapport (Rule & John, 2011) and gain a general sense of what community integration means for each participant. Interviews were approximately 45 minutes long to ensure that participants did not experience fatigue. A second 45-minute interview was conducted after initial interviews were transcribed in order to gain further information on pertinent issues raised in the first interview, and to elicit new information which participants might have thought about in the interim. Additional probing about key issues was indicated after the first level of analysis to ensure that the study objectives were met. During our contact times I remained cognisant of their potential attention and concentration difficulties due to their mental illness. A member-checking<sup>21</sup> interview of approximately 30 minutes was negotiated with participants after final analysis was completed to verify findings and seek consensus about, or modification of lead themes.

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<sup>21</sup> See 3.10.1.

### **3.7.2 Resource mapping**

Resource mapping is used in psychosocial rehabilitation to identify support and service networks (Rössler, 2006; Slade, 2009; Townley et al., 2009). During the first interview participants were asked to draw a map of places they frequent in their community with a focus on their occupational engagement. They were given a page and colouring pens with which to draw a map. The following instruction was given at the start of the exercise:

*“I am interested in how you spend your time and what your interests are. I would like you to draw a map of your community. This will help me understand the things you do every day, the places you go to and the people you meet.”*

Participants drew and labelled their maps in silence and the recorder was off during this time. Once their map was completed and they were ready to explain, we proceeded with the interview and the recording thereof (see sample map in Appendix G).

### **3.7.3 Observations**

Observations made during the interviews were recorded as field notes. These notes were made immediately after interviews to ensure reliable information was recalled (Ryan & Bernard, 2003). Field notes included jotting down the participant’s own words where these could be recalled verbatim, their meanings of community integration, experiences of the Gateway programme, my assessment of their mental state and coherence in the interviews as well as any non-verbal reactions. I noted my observations on their level of participation, my feelings, perceptions and experiences, as well as my observations on their interactions with others as these arose before or after the interviews.

### **3.7.4 Journaling**

I kept a reflective journal throughout the research project. It was used to record, question and disclose my assumptions and make arguments and counterarguments throughout the data collection phase (Dhunpath & Samuel, 2009; Harris & Bretag, 2003). During the data analysis phase, information from my research journal which recorded observations and personal reflections about the study process and participants, was used as an additional data source to support findings. I recorded the following assumptions before the study commenced:

- The Gateway programme could impact MHSUs positively and negatively.
- The Gateway programme emphasises work and helps MHSUs transition into work.
- Men are able to take time out from their lives to attend the Gateway programme more easily than women.

### **3.7.5 Document review**

As this was a case study, secondary data was collected and analysed through a review of pertinent documents. Permission to access these documents was secured via the Western Cape Government ethics approval process reference RP156/2013 (see Appendix C). I reviewed policy documents, mission statements, protocols, standard operating procedures, referral documents, public documents and the daily and monthly programme of Gateway to compare the perspectives of the research participants with the policy intention (see Appendix H). I read each document and then completed an analysis worksheet for each one. The worksheet assisted me in systematically recording information to capture data related to:

- type of document

- physical characteristics of the document
- date it was written
- author
- intended audience
- purpose of the document
- questions raised by the document

Engaging in this process allowed me to corroborate findings across data sets and served as a means of data and methodological triangulation (Bowen, 2009).

### **3.8 Data management**

All interviews were audio-recorded and transcribed verbatim into text documents by myself. Following transcription, data was organised and securely filed electronically using pseudonyms for each participant. A backup copy was stored online as well as on a flash drive and all electronic copies were password protected. The maps drawn by participants as well as all programme documents and journal entries was kept in a locked drawer that only I had access to. Where possible all data was managed electronically. A computer software data analysis programme called NVivo (Creswell, 2007; QSR International, 2013) was used to manage the data in terms of initial coding and sub-categorisation.

### **3.9 Data analysis**

By transcribing the audio-recordings myself, I immersed myself in the data from an early stage. I conducted a thematic analysis of the data, given that I was interested in the content of what was said about community integration following admission to a step down/step up rehabilitation programme as

reported on by participants (Riessman, 2008). I was mindful that I was listening to transform the spoken word into a written representation (Riessman, 2008).

### **3.9.1 Within-case analysis**

I conducted a within-case theme analysis to identify issues within each case that spoke to the genesis of community integration after admission to Gateway. My immersion in the transcription process familiarised me with the data. This assisted me in the initial development of codes. After all interviews were transcribed I reviewed my database and considered all field notes, reflective notes, audio and visual images and policy documents in order to form codes and initial sub-categories (Creswell, 2007).

As a means of organising the data, I read individual transcripts bearing the research objectives in mind. I read each transcript a few times in order to identify key points to follow up on in the second round of interviews. I developed detailed descriptions "*in situ*" (Creswell, 2007, p.151), considering the participant, place and providing a detailed description of what I saw. All information was colour-coded. After the initial Nvivo coding, I read the subsequent interviews looking for commonalities and differences in the light of the case study, and seeing if any trends emerged. Through inductive analysis codes addressing each of the research objectives were ascertained through a process of identifying and naming meaningful segments. Information from the document analysis was used to provide supplementary data.

### **3.9.2 Cross-case analysis**

Cross-case theme analysis was undertaken in order to identify issues or categories that were common to all. I embarked on what is referred to by Creswell (2007, p.185) as “*winnowing*” the data. This required me to examine all the data across the five cases and identify tentative categories and subcategories though combining codes common to all. I also looked at differences across the cases that could indicate anomalies. This was done against the backdrop of the research objectives. Analysed documents were used to corroborate or refute findings. Throughout this process I was aware that a thematic narrative analysis favours the organisation of categories around a central theme but I was also mindful of the variation in meanings for individual participants.

I followed the data analysis framework suggested by Creswell (2007, p.183) namely the ‘data analysis spiral’. This framework, depicted in Appendix I, involved the steps of reading, memoing, describing, classifying, interpreting, representing and visualizing the data. It is a spiral process where data collection, data analysis and the writing up of findings are connected and not treated as distinct, linear steps.

### **3.10 Ensuring trustworthiness**

In their seminal work, Lincoln and Guba (1985) suggest that assessing the worth of a qualitative study can be done through establishing trustworthiness via four key elements namely: credibility, transferability, dependability and confirmability.

### **3.10.1 Credibility**

Credibility refers to the confidence I have that the findings are a true interpretation of the participants' original data (Lincoln & Guba, 1985). Techniques used to establish credibility in this study included peer debriefing (by supervisors and presentation to fellow postgraduate students), triangulation, and member-checking. Data source triangulation was used to decrease bias that comes from only using one data source. I thus collected data in different ways (interviews, observations, resource mapping and document analysis). These multiple data sources assisted in providing thick descriptions across situations (Stake, 1995). Credibility was obtained through employing the resource mapping as an additional data generation method and using the map to collaborate information shared by participants (Flick, 2009).

Member-checking was used to ensure that the participants' voices were carried through in my representation of their stories. I allowed them to review the transcripts of the first interview so that they could comment on what was captured. I returned to them after data analysis and in so doing, suspended my own interpretation and assumptions while giving them the opportunity to comment on whether the development of themes and categories were a reflection of their lived experience (Lincoln & Guba, 1985). My literature review revealed a debate on member-checking in some qualitative studies (Morse, Barret, Mayan, Olsen, & Spiers, 2002), but its use in this study is supported as a technique with which to confirm whether findings are authentic and original.

### **3.10.2 Transferability**

Transferability refers to the extent to which the findings can be applied to other contexts and participants and it is usually an important measure of the

validity of a study. Due to their context specific nature, qualitative studies have limits on their transferability and their representativeness (Kelly, 2006a). Transferring the views of this group of male MHSUs can thus be contested. Qualitative studies invite their readers to make connections between elements of the study and their own research interests. To create a foundation for transferability I have provided detailed information on the research situation, context, methods, participants and research process. This, coupled with purposive sampling and the use of verbatim quotes to support codes contribute to thick description which could enhance transferability opportunities to facilitate pragmatic use of knowledge (Kelly, 2006a; Morse et al., 2002). Case study research generates context-dependent knowledge as it stems from reflexive selection in the case of interest. Through its focus on the 'little things', (Riessman, 2008, p.194) case study research is useful in generating knowledge on occurrences in the social world and how these create depth in terms of contributing to the accumulation of knowledge.

### **3.10.3 Dependability**

Dependability was addressed through the generation of an audit trail (see Appendix J) in order to create a dependable account of the research process. NVivo was used to store and organise audit trail elements in order to keep the research process logical, traceable and clearly documented (Graneheim & Lundman, 2004; Lincoln & Guba, 1985). Folders were assigned to each element and in this way the consent forms, original transcripts, audio recordings, community maps, photographs of interview sites, fieldwork memos, interview notes, reflexive journal entries, data analysis documents, member-checking comments, peer review comments and data interpretations, revisions and recommendations were stored in one place. Competent peers (supervisors and colleagues) were appointed as auditors to address issues of dependability and confirmability (Lincoln & Guba, 1985). Throughout the supervision process they were asked to

analyse portions of data after which I consulted with them to clarify agreement and explore my own analysis and clarify my decisions. Using NVivo I recorded how data was grouped first into codes, then collapsed into subcategories and categories. The audit trail thus allowed me to link findings with the raw data (see Appendices J and K).

#### **3.10.4 Confirmability**

Confirmability was promoted through triangulation and reflexivity. My reflexive journal allowed me the space to circumscribe assumptions and suspend my personal beliefs about the Gateway service and its impact on community integration. This allowed me to present participants' views on this, and not my own. This was important as my identity as the researcher, a female and an occupational therapist crossed intersections of race, gender, religion and age in relation to the participants and this impacted on co-construction of meaning (Riessman, 2008). Document analysis increased triangulation by providing a verifiable backdrop to participants' retrospective comments on the residential-based rehabilitation service.

### **3.11 Ethical considerations**

The ethical principles of autonomy, non-maleficence, beneficence and justice guided the research (Wassenaar, 2006).

#### **3.11.1 Autonomy and respect**

All participants were informed about the purpose, risks, benefits and procedures involved in the study through the information sheet (see

Appendix D). Participants' right to be fully informed and to participate or withdraw from the study without fear of repercussions, was respected through giving them the choice of participating and giving me voluntary informed consent (Appendix E). People with psychiatric disorders are considered to be a vulnerable group (Wassenaar, 2006), and as such I was aware that their abilities to exercise choice and free will might leave them susceptible to coercion and exploitation. It was thus important that they understood the purpose of the study in order to give informed consent while upholding their autonomy.

Confidentiality and their right to privacy and anonymity was ensured by the use of pseudonyms in the research report, interviewing them at locations of their choosing and refraining from discussing them with any person besides the professional staff directly involved with their mental health care if the need arose. While confidentiality was ensured upfront, I also had to consider the participants' right to privacy in the way I described the mental health services they use and the suburbs in which they live, especially if this information could be paired with other descriptive information related to time of admission to Gateway and subsequent interactions with the health system.

### **3.11.2 Non-maleficence**

As an experienced mental health practitioner I am equipped to discern fluctuations in mental state, to respond appropriately and to refer timeously. At every stage of the study I ensured that no harm befell the participants. I referred one participant, Bolo, to the mental health nurse for psychological support when I assessed that his mental health was deteriorating. Risks to participants were minimal but in cases such as the one mentioned above timeous referral was made. Bolo completed the study and was seen by the mental health nurse two days later but a hospital admission was not required. At the time of the interview he admitted to having smoked drugs

and this could have influenced his presentation at the interview. In this case the dilemma I faced was that a referral to the mental health nurse meant that I had to call in an external person when I queried Bolo's mental state. The cause of his confusion could be attributed to his engagement in activities that put him in harm's way (substance abuse). Consequently I was under an ethical obligation to see that he does not harm himself or others and I informed him that I would be referring him to the mental health nurse for follow-up. Throughout the study I modelled self-awareness as the influences of my experiences assisted me in judging the rigour of the research. I used my reflexive journal to continuously pose the following question to myself, "Will this information cause harm to male MHSUs if it is asked and if it is shared?"

### **3.11.3 Beneficence**

The research is aimed at informing public mental health service delivery programmes on what the contribution of residential-based rehabilitation services is to community integration from the perspectives of male MHSUs. In this way the research intends to contribute towards 'public good' (Flick, 2009). I considered the minimal personal risk of participating in the study with the benefits of having MHSUs share their perspectives and how this could contribute towards society in terms of mental health service related knowledge gained (Kleintjes & Lund, 2010). Crowe et al. (2011) supports the use of the case study approach in healthcare service delivery as a means of gaining insight into policy developments, health service reform and interventions.

### **3.11.4 Justice**

According to Wassenaar (2006), justice requires that participants receive what is due to them and that they are treated with fairness and equity throughout the research process, and that they have access to care and support should they become distressed in the study. I considered this in advance and addressed support structures for them to access in the information sheet (Appendix D). I also demonstrated this practically through my referral of Bolo as previously explained.

Participation was voluntary and participants were not remunerated for their participation but the principle of justice was ensured by the dissemination of information learned in the study. As part of their descriptions of what community integration entails for them, participants shared their engagement in harmful and illegal activities (trading in stolen goods and using illicit substances). While I was obligated to disclose criminal activity in the study through presentation of information shared with me, I remained bound to the confidentiality contract that I agreed to with the participants. If the authorities requested that I divulge this information I would have informed the participants beforehand as the information had to remain confidential unless the MHSU was in danger of harming themselves or others as is required by the MHCA. Such a situation did not arise during the study.

### **3.12 Summary**

This chapter outlined the constructivist theoretical approach used in this study and motivated the instrumental case study design chosen for this research. The research context and participant selection criteria and process were explained. Details were provided on the data management, ethical considerations and approach to ensuring trustworthiness. Given the

constructivist lens within which the research was framed, the findings of the research are presented in the next chapter.

## CHAPTER 4: THE PARTICIPANTS

### 4.1 Introduction

The chapter introduces the five participants. It presents their biographies, diagnoses and living arrangements based on the within-case analysis. Pseudonyms are used to protect the identity of the people and places concerned.

### 4.2 Participants

#### 4.2.1 Mikaeel

Mikaeel is 55 years old and he has been living with a mental disorder for 30 years. He has paranoid schizophrenia and is able to describe what this diagnosis means for him and how he lives with it. His explanations of his subjective experiences supported with his knowledge of the signs and symptoms of the illness are a testament to his intellectual insight. Mikaeel completed high school and studied psychology and philosophy at university for two years, after which he dropped out due to financial reasons. Over the years, he has not had any stable employment; instead he held a number of different jobs. At the time of the research he was unemployed.

*“My first job was interviewing people, correcting information then I worked in the theatre at CAPAB; I worked there for a while and then I did auxiliary work in mental health and what have I done since then, other small little jobs...a week or two for a plumbing ...Ja that was just an odd job. I even worked in a control room for security. I’ve done lots of bits and bobs.”*

Mikaeel is well spoken and was tidily dressed for the interviews. His hair was tied neatly in a ponytail and his fingers were stained yellow from smoking. He lives in a group home, Support House<sup>22</sup>, located in an affluent suburb in Cape Town. He welcomed me warmly to conduct the interviews there. He shares the house with eight other people, each of whom has a mental disorder. He has lived at Support House for ten years and his social grant is used to pay for his accommodation. Mikaeel does not live in the main house; instead he has a single room in the backyard. His room is small and has just enough space for a single bed, single cupboard and desk littered with books. His room overlooks a small well-kept garden area, which he tends.

For Mikaeel, living in Support House meets his basic needs of food, laundry, shelter and security. All grocery shopping, laundry and meal preparation is done for residents by the day mother during weekdays. She does not work over weekends, when residents are responsible for their own meals. Residents are assigned daily chores, which are their responsibility. They have to budget for their own personal care products and luxuries.

Support House does not meet Mikaeel's social needs. To meet these needs he frequents accessible public spaces (within walking distance of Support House) on a daily basis. In these public spaces he reported having peace of mind because most of the people he meets are unaware that he has a mental disorder.

*“So now I leave the people with the illness here [Support House] and I go out...I try to go to places that are friendly, and uhm, as I said, there's very little consciousness of being ill, because I'm just a customer, the guy who sits and drinks coffee, so it's public spaces”*

Being able to socialise without disclosing or foregrounding his mental illness, leaves Mikaeel feeling integrated. He is satisfied with having casual acquaintances and expresses that he does not seek intimate relationships

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<sup>22</sup> The pseudonym was used to ensure anonymity of the group home. The name was selected as a reflection of the benefit that Mikaeel derives from living there. It is affiliated to an organisation, which provides accommodation as well as a daily clubhouse service for socialisation, support and craft opportunities.

beyond his “go-to people”. He identifies these “go-to people” as his family and the stable mental health support network that he has access to. Mikaeel reported using these supportive relationships at different times during the month. Taking care of his health in this way frees him up to pursue ventures which will enhance his community integration agenda.

*“When it comes to my health there’s three places: this house, the office, the outpatients that give me support. I have to go to the office once a week and to the counsellor once a month. We all have our duties to do in the week so I collect mail and then I see a counsellor there once or twice a month and then I go to OPD for my meds ”*

He considers the time he spent at Gateway as an opportunity to learn about his stressors and triggers in a structured environment, although the inflexibility of the programme did not meet his personal needs. He recognises that having a mental illness makes him withdrawn, and the programme, through its emphasis on group participation, forced him to interact with others. However these connections have not continued outside of the programme. Although he recalled receiving individual sessions at Gateway he was unable to explain what these were, what he gained from the sessions or how or by whom they were offered. The document analysis<sup>23</sup>, presented later, confirmed that individual sessions were not reflected on the weekly programme and were offered on a needs basis.

#### **4.2.2 Bolo**

Bolo is 29 years old and was diagnosed with schizophrenia ten years ago. He struggled to give a coherent account of himself, often losing his train of thought as he related a story or attempted to substantiate statements. These illness symptoms frustrate him and he expressed seeing himself as stupid

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<sup>23</sup> *“Clinical pathway and referral pathway: Family and individual clients appointments. Individualised treatment plans are formalised with the patient”* (Associated Psychiatric Hospitals, 2010; Occupational Therapy Department, 2011a, 2011b).

and unable to learn. His verbal and written communication in English and Afrikaans was poor as was evidenced when he labelled his resource map and in the excerpts included in the findings. Bolo did not complete primary school nor has he ever been formally employed.

Bolo lives in an overcrowded, rented, government-owned property on the Cape Flats. He lives there with his mother, brother, two aunts and four cousins, and he sleeps on the floor in the sitting room. I met him at the local library and his mother accompanied him on the first visit. Bolo is shy and reserved and appears younger than his 29 years. He wore cut-off denim shorts and carried a hardcover book under his arm to both our interviews. He would not reveal the contents of the book, saying he brought it along to collect ideas even though he never used it to write down anything during the interviews.

Bolo shows an entrepreneurial spirit, although not always accessing money by legal means. He is involved in various informal income generating activities such as buying and selling stolen clothing and mobile telephones, selling firewood, gardening and gambling<sup>24</sup>. He shares frankly how he steals from his family and friends; and then sells their belongings to a readily available market of buyers in order to source cash so that he can buy drugs and gamble. He feels integrated into this community of informal entrepreneurs through his willing engagement in the readily available bartering opportunities in his neighbourhood, even though these place him at risk for physical assault, arrest or imprisonment. He was previously imprisoned for theft, but the case did not proceed to trial because he was found to be mentally ill at the time of committing the alleged crime and he was referred to Horizon hospital instead.

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<sup>24</sup> The informal economy which includes fraudulent activities contributes between 4-6% of the GDP of South Africa (Ligthelm, 2006).

Bolo roams the streets during the day, returning home only to sleep. He abuses substances<sup>25</sup> and disclosed that he smoked tik<sup>26</sup> the evening before coming to the second interview. He presented at the interview as distractible, unable to curb his desire to speak loudly in the library and his thinking was disordered<sup>27</sup> which caused me to query a relapse. I encouraged him to visit the mental health nurse and I called her to express my concerns. She met with him, and although a hospital admission was not required, he was subsequently referred to the ACT team.

### 4.2.3 Gershwin

Gershwin is 39 years old and has had bipolar mood disorder for ten years. He is torn between trying to build his life independently and lacking the motivation to do so. The ambivalence he feels towards many things in his life mimics his diagnosis. His medication subdues him, causing feelings of sadness, which result in his inability to do the things he needs or wants to do.

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<sup>25</sup> A South African study on illicit drug use amongst urban dwellers conducted by Peltzer, Simbayi, Kalichman, Jooste and Cloete (2009) found that drug use amongst participants were as follows: 25% for cannabis, 7.3% for methamphetamine (tik) , 5.4% for mandrax, 3.3% for pills from the street and 1.2% for any drug injected by needle. Additionally they found that over a 12-month period nearly one in three urban dwellers showed symptoms of drug addiction.

<sup>26</sup> Worldwide, tik use is the highest in Cape Town with 90% of users being coloured (Plueddemann in Kapp, 2008). According to the South African Community Epidemiology Network on Drug Use (SACENDU) the drug was originally introduced to Cape Flats communities as part of gang culture (Kapp, 2008) although its use has now spread more widely. The South African Medical Research Council (MRC) reports tik as being the primary or secondary source of abuse for which people seek treatment (Kapp, 2008). In this regard it is ahead of alcohol abuse. An increase in drug use in the Western Cape has a number of consequences which include the following: influence on sexual risk taking which increases risk of HIV infection, increase in heroin addiction accompanying use of tik, long term psychological effects of tik has seen an increase in psychiatric admissions amongst users, low- birth-weight of babies born to women who abuse tik and an increase in tik-related crimes (Kapp, 2008; Peltzer et al., 2009).

<sup>27</sup> Bolo's thinking was illogical and tangential. His memory was poor and he had psychomotor retardation.

Gershwin agreed to meet me at the Horizon hospital OPD. He was initially reluctant to participate, as he usually stays home waiting for a telephone call in connection with a job he applied for. Gershwin waits for this call and only leaves his home to attend his monthly OPD visits. Between the two interviews he received the long-awaited call offering him a job. He accepted it even though it was not the job that he had applied for. Since his diagnosis he has only managed to secure ad hoc employment.

After explaining my study to him he suggested asking his father to work from home on our interview days so that he does not miss his telephone call<sup>28</sup>. Gershwin cycled to the interviews at the local library and he was neatly dressed at all times. He wore a large ring on his left middle finger and said it was related to his days as a martial arts student. Before our first interview he indicated that he was hungry. I had a cool drink; sandwich and fruit but he did not deem these able to satisfy his hunger. Sensing that I was somehow being tested<sup>29</sup>, I agreed to buy him a pie and we went to a nearby shop. Gershwin shared his surprise at my willingness to walk in what he deemed the dangerous part of the suburb, all the while pointing out personally significant landmarks.

Gershwin lives with his parents in the house where he grew up. His grandmother lives close by while his younger sister lives overseas. The neighbours are his friends and these are the people who know he has a mental disorder. This network of people 'who know', serve as his core social circle and he does not deem it necessary to develop new relationships. He

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<sup>28</sup> Extract from Reflective notes: 12/02/14 Met Gershwin at OPD today to explain my study. He was there to see the doctor and wanted to meet me first. He was wearing a T-shirt with "I'm socially responsive on it". What an interesting person. He agreed to participate saying he has lots to say!

<sup>29</sup> Reflective notes 18/02/14: I called Gershwin on Monday to remind him about today. When I got to the library he had been waiting for a while (according to the librarian he came an hour before our scheduled appointment time). He said he's hungry and wants to eat first, but wants to choose his own eats! He really pushes the boundaries and I feel as if he is testing me. I agreed to go to the shop with him, and I could sense his surprise that I would walk in the area with him. I think I passed that test! It is not unlike where I live but my willingness seemed to set the scene for cooperation.

finds pursuing new friendships too energy-consuming as he is always confronted with whether or not to disclose his mental disorder.

Gershwin holds a tertiary qualification and had been working as a disc jockey for ten years at the time of his first admission. Being a disc jockey was a social occupation that he felt unable to resume after his admission. He attributes this to his reluctance to explain his absence to people and the stigma associated with having a mental disorder. For Gershwin the experience of living with a mental disorder means he is selective about whom he spends his time with, what he spends his time on, where he accesses his support and when and to whom he discloses his mental disorder. His parting words to me summed up his stance that he is integrated because he exercises these options.

*“There’s always something that is hidden in your community integration. So if you want community integration to be a successful thing, you have to keep certain things hidden.”*

#### **4.2.4 Emmanuel**

Emmanuel is 31 years old and has had a mental disorder for 13 years. While his current diagnosis is schizophrenia, he was also diagnosed during one admission as having bipolar mood disorder. He says the time he was ill was painful and confusing because he acted on his delusions, which resulted in him physically harming himself<sup>30</sup>. While listening to him reflect on this time, it was difficult for me to distinguish between what was real and what was not<sup>31</sup>.

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<sup>30</sup> He was watching television (TV) and had the delusion that it was the end of the world. His auditory hallucination led him to believe that the TV was telling him what to do. He acted on his delusion and hallucination by swallowing barbed wire and floor polish and when he told his parents they prayed for him and called the Reverend who took him to hospital. He had to have surgery to repair the damage caused by the wire.

<sup>31</sup> Research journal note 12/02/14 “...also he goes off on a tangent quite a lot so I had to bring him back while still being mindful of the need to give him time to talk and let things evolve.”

He reported that despite the doctor's repeated explanations at the time, he remains confused about what happened.

Emmanuel met me at the Horizon hospital occupational therapy department. He was always smartly dressed and on one occasion he donned a suit, as he was en route to a disability information summit at the Cape Town International Convention Centre (CTICC) in the city. Emmanuel lives with his parents in a township<sup>32</sup> on the Cape Flats. He spends much of his time, with curriculum vitae (CV) in hand, travelling across the city by foot, train or taxi trying to secure a job.

Emmanuel told me that his name means "glory" and his Christian beliefs surface throughout his story. He sees his most significant social activity as attending church, but his view that the church fails to recognise the legitimacy of mental disorders and its effects on people, causes him distress. He feels compelled to choose between the church<sup>33</sup> and pursuing a romantic relationship, and is preoccupied by which choice will secure his future happiness.

Despite his inner turmoil, Emmanuel shares that reminiscing about his admission to Horizon and Gateway and subsequent community integration helps him to make sense of his personal history, current situation and the future. At times he displayed tangential thinking, hopping from one topic to the next and some of his explanations were hard to follow. Emmanuel considers himself recovered but concedes that recovery is ongoing and complex. For him full recovery means living independently, maintaining his relationship with his girlfriend (whom he has been dating for one year), being accepted by the church and securing a job. These real life dilemmas both energise and exhaust him.

*"Yes, I am [recovered] but I still need that bit of the stableness in my well-being even though I'm saying I'm recovered...and then also the housing*

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<sup>32</sup> A low socioeconomic residential suburb with formal and informal housing designated for black people in the apartheid era.

<sup>33</sup> While part of this confusion is related to Emmanuel's thinking it is also an indication of how complex community integration is for persons with chronic mental illness.

*...and then maybe in other directions, get a job and stay in with this girl of mine. Even though I don't know if we are going to get married. It's kinda difficult. My life is complicated, hey?"*

#### **4.2.5 Dan**

Dan is 27 years old and was diagnosed as having schizoaffective disorder five years ago. He was referred to me by the social worker at Community Care Place<sup>34</sup>, a local non-profit organisation (NPO) which he attends because it provides community-based mental health services to people living with psychiatric disorders. He has been living at Safe House<sup>35</sup>, which falls under the auspices of Community Care Place for a year, although the first six months was spent in hospital where he was treated for multidrug-resistant tuberculosis (MDR-TB). He spends a large part of his week travelling to different clinics for his TB and psychotropic medication<sup>36</sup>. Free mornings are spent at a clubhouse for people with mental disorders.

We met in the kitchen at Safe House, which is relatively quiet in the mornings as the 13 residents leave the group home between 9h00 and 13h00 daily. At the time of our initial interview, Dan was given two week's notice for violating one of the house rules when he abused substances. He had entered into an agreement that he would abstain from drugs and alcohol, accept regular urine tests as evidence of abstinence and attend regular narcotics anonymous (NA) groups. At the conclusion of the study he was still complying with his agreement conditions. Dan is a tall young man who

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<sup>34</sup> The pseudonym, Community Care Place was used because it is reflective of the organisation's aim of supporting people with psychiatric disabilities in community living.

<sup>35</sup> The pseudonym Safe House was used based on a quote from Dan that living there made him feel safe.

<sup>36</sup> Dan collects his TB medication at one clinic, which he attends, on alternate weekdays as part of the TB adherence programme. In addition to this he attends a monthly clinic in another suburb where he collects his psychotropic medication for his psychiatric disorder. There is currently no integrated clinic that is able to offer him both these services.

favours shortly cropped hair and dressing in T-shirts and shorts. He yawned frequently during the interviews, which he attributed to being tired.

Dan shared his frustration with the lack of local recreational opportunities for people who do not drink alcohol. While trying to maintain sobriety and going about his daily business, he was repeatedly confronted with opportunities to use illicit substances. Drug dealers approached him while he was using public transport and when he worked with a friend they were asked to buy alcohol for their employer.

After his parents' divorce, Dan lived with his mother while attending a secondary school in the Southern suburbs where he completed Grade 12. He did not pursue further studies after secondary school. Since leaving school he has held down a variety of jobs ranging from work in the navy and food industry, to doing manual labour. Dan's mother had a history of mental illness and substance abuse. When she passed away from cancer in 2004 he went to live with his father. His father evicted him for abusing substances and he lived with different people over the years. Before joining Safe House he was homeless and lived at a night shelter. He also spent some time in prison while he was awaiting trial for motor vehicle theft and possession of illegal substances. The case was dismissed due to insufficient evidence against him but it culminated in him being admitted to Gateway for six months instead.

*"I was sent there because I was in custody at Pollsmoor Prison because I was a potential for [forensics observation unit] because of the two cases I had pending against me. I was fortunate enough not to get a criminal record because at Horizon they told me that it wasn't a serious enough case for me to be admitted there and I didn't spend a month in [forensic observation unit] I spent about two, three days and they sent me back to Pollsmoor and within about 2 weeks of constant court cases every day I got allowed to get admitted to the Horizon hospital high care and they sent me to Gateway."*

Dan is currently in a new romantic relationship. His girlfriend holds down a job and is aware of his mental health and substance use struggles. Dan is

optimistic that the challenges he faced in previous relationships where he engaged in smoking and drinking with his partner will not be an issue in this relationship. He has a network of health professionals supporting him and monitoring his health status. He accepts this public sector professional network as part of his life and is co-operative because his place at Safe House hinges on it.

### **4.3 Conclusion**

The brief biographies of the five participants presented in this chapter allude to the personal-environmental dynamics at play in each person's community integration story. The impact of the negative symptoms of mental illness on each data-gathering interview also becomes evident. The findings of the cross-case analysis are presented in the next chapter.

# CHAPTER 5: FINDINGS

## 5.1 Introduction

This chapter explores the central theme and its associated categories resulting from the cross case analysis of participants' collective experiences of community integration. Findings arising from the document analysis are included throughout the chapter. Quotes in Afrikaans are followed by an English translation. The theme 'It's a catch-22 situation' consists of three categories, as indicated in Table 5.1

Table 5.1: Overview of the findings

<b>Theme</b>		
<b>It's a catch-22 situation</b>		
<b>Category 1</b> <i>It's not just what you call it</i>	<b>Category 2</b> <i>There is no one size for all</i>	<b>Category 3</b> <i>It's tricky choosing between places to go and things to do</i>

In the first section of the chapter the central theme is introduced. Thereafter each of the three categories and their supporting evidence are described.

## 5.2 Theme: 'It's a catch-22 situation'

The theme 'It's a catch-22 situation' reflects the ambivalence that the men feel as a result of the tension between dealing with the personal meaning of

having a mental illness and accessing a range of services because of their diagnosis.

The places and activities available to MHSUs in their communities revealed paradoxes associated with community integration. These paradoxes were not overtly addressed during or after their admission to Gateway. The MHSUs did not identify their Gateway experience as supporting their community integration; rather it was recognised as a time of respite from their stressors. The MHSUs were caught between the recovery benefits of this respite period and the inevitable realities of actually coping with a severe mental illness in daily community life.

*“So I mean I’m in a catch-22. I never asked for it [mental illness] but I always get told that I should be grateful that I’m one of the lucky ones who got seen and got help but it also has its weighing burdens that’s not gonna get any lighter.” (Gershwin)*

The intention of the Gateway service is to provide “*alternative, residential-based recovery and rehabilitation services for people with severe mental illness*” (Associated Psychiatric Hospitals, 2008b) and as the findings in each of the categories illustrate, these services do not adequately address the complexities of community integration. Gateway “*acts as a cushion between inpatient hospital care and the general community... with a focus on strategies for a balanced, healthy independent life*” (Associated Psychiatric Hospitals, 2008a), yet the findings show that the programme content does not address the individual meaning of what a balanced life in community entails. The theme, ‘It’s a catch-22 situation’ speaks to the predicament that MHSUs face: an unwanted mental disorder on the one hand and desired community integration on the other. An in-depth exposé of each category now follows, showing the details of how the MHSUs come to experience community integration as ‘It’s a catch- 22 situation’.

### 5.3 Category 1: 'It's not just what you call it'

This category describes the tensions that MHSUs face when they are treated as homogenous patients, rather than as individuals when accessing mental health services. The inclusion criteria for admission at Gateway specify that an individual should have at least one of the following diagnoses: schizophrenia, schizoaffective disorder, bipolar affective disorder or first episode psychosis. This diagnosis allows the professionals to categorise the illness and identify treatment options, but it does not capture the meaning and challenges that the person living with a mental illness faces. Despite sharing a label in the form of a diagnosis, the label does not mean the same thing to each of the MHSUs.

*"In 2002 they told me about this thing, schizophrenia, they told me, actually sister Bonnie<sup>37</sup> was there and she asked me: "Did they tell you what sickness you have?" So she told me you have schizophrenia. I would see Santa and his reindeer flying. It was real to me but others would disagree with me... I actually didn't understand it, it was more than the same thing that I had when I was stressed, like they were discussing my life and I have this bipolar mood disorder with me. In 2009 I went to Horizon hospital for bipolar."*  
(Emmanuel)

Living with a mental illness affects MHSUs differently. The experience of the illness is more than just the label or the symptoms. Bolo speaks about his confusion and on-going struggle in learning what his illness means to him personally.

*"Uhm, maar ek weet nie met wat nie- hulle het gese schizophrenia of bipolar maar ek weet nie." [Uhm, but I don't know with what- they said schizophrenia or bipolar but I don't know]... You see, Fadia, stress can be a lot of things on your mind that you can't explain it. It can be like vrot [decayed] in your mind, vrot [decayed] in you mind, it can be like you won't get it out..."*

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<sup>37</sup> Pseudonym used.

Admission to Gateway and Horizon hospital limits the MHSUs autonomy.

*“And where my rights got taken away. People telling me when I can do, what, where I am, what to do, taking 16 tablets a day, and uh my hate for that chain became from there, because every time they didn’t know what was going on, or couldn’t understand they would ship me off to Horizon and obviously I would be more upset, more in temper.” (Gershwin)*

Not raising the doctors concern about his mental state was one way in which to prevent an admission to Horizon hospital, cause a change in his medication or result in an increase in OPD appointments, all of which might have curtailed his community integration.

*“The doctor he reads up on the last notes from the last time we spoke and he asks you the three main questions: “Do you hear voices? Are you suicidal? Does the TV talk to you?” and the simple answer is no. You don’t play around with those questions. You just answer no and you’re finished. The doctor will think to himself you very fidgety today and he will ask you: “you’re fidgety today” and then with the slip of his pen he will scratch out apsychotic and put down psychotic, so you know it’s very simple for things to change if you make the doctor believe that there is something else happening.” (Gershwin)*

MHSUs are aware of the power held by the professional’s assessment of their mental state. Even though Dan disagreed with the social worker’s assessment of his affect he did not convey this to her for fear of the consequences.

*“Ja, it’s schizoaffective disorder. I always thought it was more schizophrenia ...my social worker’s name is Clio<sup>38</sup>, uhm, she sometimes says that I have a very wooden appearance and that I don’t have much facial expression but I felt like telling her that she’s spending too much time with Boyd<sup>39</sup> [fellow resident] because he is another individual that always over-*

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<sup>38</sup> Pseudonym used.

<sup>39</sup> Pseudonym used.

*exaggerates his facial expressions, so that's what I find, so I disagree with her but I won't say it because she'll probably take offense if I did."* (Dan)

Gershwin expressed his disagreement with how others attribute all his actions to his diagnosis.

*"My diagnosis is bipolar and I have manic episodes as I am led to believe. You know before I was diagnosed with bipolar I could do 30 things at once and no one complained. Now I have bipolar and it's you can't do 30 things at once, you're manic..."*

Making sense of their illness is an on-going personal journey, which takes time.

*"It takes 30 years to realise that. Look like in my case I have paranoid schizophrenia uhm, you know, so there is always suspicion and fear and that type of thing...You have this tendency towards conspiracy theories...that is the way things are...It means different things to different people. My schizophrenia is not like yours; it's very different from person to person, so even though we have the same title (laughs) if you like, but it's very different."* (Mikaeel)

One of the objectives of Gateway is to provide *"psycho-education for patients and family regarding illness and importance of treatment adherence"*. Gateway's objective is focused on a medical model of recognising and managing the symptoms but does not cover the practicalities facing the MHSUs and their families once the person is discharged.

*"The priority is the family and getting them to back off... because you as a human being won't tolerate to a certain point people meddling in your life. You'd say: "Stop now, this is enough, it's my thing, my problem." You've got to get them to a certain point to back off..."* (Gershwin)

There is a cycle of guilt and self-doubt experienced by all parties affected by the mental illness, illustrating another layer in the catch-22 theme. The dilemma that the family faces is being able to discern what kind of support is needed once the MHSU is in the community. Although Gershwin recognised

his parents' positive intentions, he experiences their care as limiting, calling it an "extended childhood".

*"What I want to say is that you are stuck in the relationship of an extended childhood for two reasons. The one is it's more than likely that your parents have put you inside an institution so they have rights over you, which means that they control you because you are still staying under their roof which is where you'll find yourself because your life is getting interrupted... your accommodation, you are not working, so you become dependent on them. So it's a vicious circle." (Gershwin)*

Emmanuel shared a similar concern related to the way that his parent's over-protectiveness affects him. He believes that his home environment coupled with his lack of motivation, denies him opportunities to take on adult responsibilities.

*"I live with my mother and father...I am lazy. I don't clean up there at home, I don't cook; I don't do any of this stuff. My mother is already doing it for me, my clothes already washing it for me, food already cooked for me. All these things. I can't say ok this I'm gonna do." (Emmanuel)*

Even though MHSUs felt unsupported in independent living, they recognised that their parents' over-involvement in their lives resulted from their diagnosis and the medical model of psycho-education that their parents received.

In summary, this category 'It's not just what you call it' revealed how MHSUs view their mental illness as only one part of their identity, a part that has to be managed as they strive for community integration. Since mental health service providers operate from a medical model and use the mental illness to define the needs of MHSUs, the particular individual needs and goals of the MHSUs are not sufficiently attended to. Community integration involves, amongst other things, the ability to manage the catch-22 dilemmas arising from their mental illness being played against their personal identity.

#### 5.4 Category 2: 'There is no one size for all'

The journey of dealing with complex dilemmas on a personal level as well as through imposed structures is captured in this category.

*"You know it's difficult when one has a mental illness; it is very difficult to speak about belonging. You know, it's very difficult, I mean most people belong somewhere but people with mental illness tend to be displaced, they don't really fit in anywhere... This belonging, where do you fit in? Who are you? In our own way we all do because we are all different."... "And there's changes all the time and it's difficult to depend on things staying the same...So there's a whole lot of layers." (Mikaeel)*

The findings reported here describe how the design of the public mental health service continuum<sup>40</sup> contributes to the MHSUs' experiences of community integration.

The involuntary admission<sup>41</sup> procedure to Horizon hospital allows for police officers to assist with getting MHSUs admitted to a psychiatric hospital. This process does not require consent from the MHSU and surfaces a tension between respecting the rights and responsibilities of the MHSU, the caregiver and the service providers.

*"And the hospital wanted to see me and the nurse wrote a letter and uhm the letter went to the South African Police and my mom came with them. To cut a long story short they came into my house, threw me over my desk, and broke my things... I was screaming to my mother to help me but she wouldn't help me, thinking she's helping me by getting me to the doctor, but they were treating me like a subhuman, they had no regard for my things, my goals, and my status." (Gershwin)*

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<sup>40</sup> In the mental health service platform, Gateway is a level of care between the specialist psychiatric hospital and the 'naked' community (integrated PHC).

<sup>41</sup> MHSUs can be admitted to a psychiatric hospital on an involuntary basis according to the MHCA if they are assessed as posing a danger to themselves or others (South African Government, 2002). Gateway only accepts voluntary patients without behavioural problems or unstable medical conditions.

Excluded from the decision as a result of the involuntary admission leaves MHSUs feeling powerless, a feeling confirmed by the lack of consideration of the person.

*“As a patient you came from a situation where you had respect and then you come into a system who doesn’t care what you say. You are in a locked ward, you do what you’re told to do, they don’t want to hear what you have to say... that can be quite an eye opener.”(Mikaeel)*

Mikaeel goes on to express insight into the dilemma faced by service providers regarding how to admit acutely ill MHSUs to hospital in a humane way while being aware that they are at risk of harming themselves or others.

*“Uhm but there are two sides to the story because on one side is the importance of getting people to calm down because by the time you get to the admission ward you’re quite hysterical. You’re freaking out, you’re angry, or whatever, so from a medical point of view they have to shut you up, just keep quiet and take meds. Their priority is to calm you and serve you. So if that is ever going to change - I doubt it. I don’t know if there’s a better way to do it, I don’t know.”*

The MHSUs identified that being admitted to Horizon hospital or Gateway jeopardised their personal affairs. The interruption to their daily lives had financial repercussions and interfered with their personal community integration process.

*“Yes because when I was incarcerated at Horizon my rent had gone out, but I had paid for my rent two months in advance and that was basically wasted money which made me more irate because I was trying to sort out something for myself, but they weren’t seeing it that way.” (Gershwin)*

The Gateway timetable does not reflect time allocations for individual occupational therapy sessions (Occupational Therapy Department, 2011b), where these stressors could have been discussed. The perceived inflexibility

of the Gateway programme resulted in Dan and Mikaeel forfeiting work opportunities<sup>42</sup>.

*“So I got this job with the Western Cape Government. I was supposed to start like the Monday, ok, and the next thing I’m in [psychiatric emergency unit] at [district hospital] so my social worker at the time; she and my sister decided no, no, no this guy definitely isn’t ready for work or whatever, but they basically pushed the thing through so that I would be admitted ...” (Mikaeel)*

*“I had an opportunity to actually have a job while I was in the [Gateway] programme and it was working at the Cape Town Dock Yard. Uhm, what happened was Gateway and the social worker says that I wasn’t fit to actually work as such, I had an opportunity to, I would have earned a lot of money but it would have been too much of an actual disturbance to the set working programme for me not to be a part of the group once a day and just come back there and sleep at night time, yah.” (Dan)*

Dan provided an example of how the programme could have been more flexible and benefited him more.

*“If I would have got to work then it would have prepared me to be outside, but they wouldn’t let me work because then I wouldn’t be a part of the groups so if it will be possible to actually go there and live and then work there once a day, then it would prepare you for the real world, but ehm, it’s more like a rehabilitation programme and it is time out ya... like you must just be introduced into the working world slowly because it’s sometimes very stressful and you know you can struggle a lot.” (Dan)*

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<sup>42</sup> Professional judgement about fitness for work of persons with psychiatric disability is limited to an assessment of the alleviation of positive symptoms allowing the MHSU to participate in the Gateway programme. It does not consider the individual work skills and access to employment resources of MHSUs in the programme. This has implications for community integration as work opportunities are not explored or protected while MHSUs are at Gateway.

While Dan might have been too ill at the start of his stay at Gateway, grading his job entry while he was still a resident could have helped him transition into and maintain his job.

While admission to Gateway is voluntary participation in the programme is mandatory over weekdays. The structured programme followed a hospital like routine that required MHSUs to wake up at 06h00 to attend to their self-care before breakfast is served and medication is administered at 09h00. This routine must be adhered to, which posed a problem for MHSUs, as it was different from their routine when in the community. The strict routine of Horizon and Gateway detracts from the MHSUs' capacity for self-determination.

*"You no-one else knows what's happening to you and, er six o'clock in the morning, there's no one else that's of your friends at home that they're getting up to shower and do those things. It's only you... So by after eight o'clock [evening] you're basically in bed and I mean for people who are 40 years old and whatever, and there are people of various ages there. (Laughs) They don't er, they don't necessarily want to be you know, be managed..." (Gershwin)*

For MHSUs this time-bound regime contrasts with community life. For example, while there are rules attached to living in the group home, they appreciate the flexibility available to develop their own routine. This practice of leaving the group home on a daily basis to work or go about your own business is important to MHSUs.

*"You know in this house, in this house there isn't much of an illness vibe going on because most of the people they go out, they work or they got their things that they do." (Mikaeel)*

The Gateway programme runs according to identified themes and follows a 12 week cycle after which themes are repeated (Occupational Therapy Department, 2011b). There were 14 group activities and eight projects reflected on the programme. The programme content is geared towards preparing residents for community integration through group-based

processes; processes that place some participants in a decision cleft between the effects of their illness and the pressure of the programme.

*“My illness made me very solitary in the sense that I like being on my own, you know, and uhm, well you know it’s, well what they do is you’re kinda contained so you have to do it. You can’t actually sit back and you know say no I don’t want to do this. You have to participate in the programme, you know...So, so it’s hectically interactive cause as I said you’re in groups all the time.” (Mikaeel)*

Groups are presented by the social worker, nursing staff and occupational therapist. Topics covered in the groups included the following: medication, rights as a patient, self-awareness, disclosure, relapse, my condition, managing my health and coping with stigma (Occupational Therapy Department, 2011b). Mikaeel and Bolo struggled to explain the particular relevance of the programme.

*“A lot of good input we got there from the staff in terms of our illness and the effects it has on us and the people around us. Some people had drug problems and a lot of input about that as well. You know, being aware of what they call the triggers, things that set you off. Ja, lots of emphasis on recovery... ehm where was I going with that story?” (Mikaeel)*

*“It didn’t help me at all because, just look how stupid am I today and I dunno, they write, write, write, but they, they say sometimes and I don’t think they say but I do everything ...uh how it must be in there and when I just uhm we get breaks also, we get sleep time ...” (Bolo)*

Gershwin acknowledges the difficulty faced by staff to cater for people with diverse needs and levels of ability while also adhering to the confines of the programme prescripts. Some participants are acutely ill and this impacts on their and others level of participation

*“Like I said there was an OT there but they didn’t think far out of the box in terms of the programme. I suppose they tried to cater to the different people there but they didn’t think much about the programme...Their criteria to get in wasn’t a massive amount of things so I was grateful that I got the*

*space because I was thinking that I need it, but their programme, I suppose because of the people in it, their programme was quite lacklustre... and people were acting just as if they were in Horizon to a strong degree, looking for cigarettes and having absurd conversations, absurd conversations.”* (Gershwin)

Exploring personally relevant topics in depth required more time and flexibility in the programme. The theme ‘It’s a catch-22 situation’ surfaces here because the programme is focused on activity-based interventions, which are disconnected from the occupations MHSUs want to engage in.

*“They did little things like write out your CV and stuff like that, but if they had a drive to get people jobs then we would’ve spent three days looking for jobs not a session plucking out pictures from a YOU magazine, sticking it down with gum. It would’ve been a concerted effort to get these people into jobs.”* (Gershwin)

The Gateway programme did not consider the erratic work history dilemma or prepare MHSUs for the world of work. Instead emphasis at Gateway securing a job in the formal market but the kinds of jobs held by MHSUs query the necessity of having a CV as networks are accessed informally.

*“I also don’t like the part of getting to interviews because it gets me to the part of wondering about when they ask about employment: “What did you do and why did you leave the job?” You see? So when I come to that part about why did you leave the job? Then why did I leave the job? Because if I show you my CV, there are many things that I did, there were many jobs but at the same time I didn’t spend long enough by the jobs through my illness so when it’s like that then it’s kinda difficult.”* (Emmanuel)

The opportunity to go out on a voluntary basis after his time at Gateway in order to try out new things provided Mikaeel with affirming objective feedback about his abilities. He did this once discharged from Gateway, as the programme did not offer opportunities to do volunteer work.

*“I thought, ok let me ask them for a reference because that was one of the reasons why I got the job [as a volunteer] and they gave me such a*

*lovely reference and here I was thinking this and thinking that and these people their minds were totally in another place. And I thought yes, I can do this and also the fact again what is going on inside my head and what is going on around me is not the same thing.” (Mikaeel)*

Bolo and Dan on the other hand engage in piecemeal jobs as they arise. These informal income-generating opportunities are sporadic and unreliable, and they position themselves in ways that will help them respond to this without the need for a CV.

*“I sms him once a day, and ehm, I had a little bit of work on Thursday in Kommetjie ehm, construction work. I dug a trench; I built with some bricks and I lay a concrete slab too...Ya it was just a day job for R100 a day.” (Dan)*

*“I just garden work, and garden work for people there in our street.” (Bolo)*

*“I deliver wood.” (Bolo)*

*“Ok, and how often does he let you work for him?” (Fadia)*

*“Once in three months, or once a month...He don’t care about me.” (Bolo)*

*“So must you go to him to check if there is work?”(Fadia)*

*“Yes I must go, I must check myself if there’s work.” (Bolo)*

Gateway does not explore entrepreneurial skills nor does it address manual labour abilities as used by Bolo and Dan.

Using informal networks to access job opportunities after leaving Gateway, was a strategy used by all participants. For Emmanuel, it was not staff but fellow residents who helped him to connect with community resources to advance his job search.

*“Someone actually gave me the file with information on it. This guy that I was with at Gateway, his name was Richard<sup>43</sup>, so he’s the one that*

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<sup>43</sup> Pseudonym used. Refers to fellow resident in Gateway programme.

*gave me this file and when I got out from Gateway I went to this place, I made a phone call to the number which was on the file.” (Emmanuel)*

This led to Emmanuel being on the database for learnerships offered to people with disabilities, although it has not yet transpired into paid employment for him.

Living at Gateway during the week provided a sense of independence and freedom from family.

*“During the week I got time to think, about what I could do better to rebuild the relationship ... so what I’m trying to tell you is that I was living on my own, I had my own space, I could visit my parents and tell them this and that. That was exactly what Gateway did in a sense.” (Gershwin)*

Having time away from his family was important to Gershwin and this outweighed the irritation that he felt towards the programme.

*“Space is very important, it gave me time away. If anything that is what Gateway gave to me. And six months is an ok time to get that. There was niggling issues; I had to pee in a cup every morning and other nonsense<sup>44</sup>...”*

For others, Gateway provided the chance to learn to live and socialise with others.

*“It taught me like compassion and stuff and living in a group community and I use it here [Safe House] because, I find it easier to live with people that I live with here in a large house full of people, because I’ve lived at Gateway before.” (Dan)*

Being in Gateway assisted Bolo in resisting the temptation to take drugs when he was home over weekends and he recognises the value in this.

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<sup>44</sup> A urine test is taken after MHSUs return from weekend leave to ascertain whether or not they used illicit drugs. A positive result could lead to MHSUs losing their place in the programme. There is a high incidence of dual diagnosis where MHSUs have a substance use disorder along with their mental disorder.

*“Ek dink is het vir my gehelp want ek kan gese het toe ek daar was en weekends huistoe gekom het, dan het ek nie drugs gevat nie... Ek het net gevoel it sal nie lekker wees om in so n plek te wees en dan drugs te vat nie” [I think it helped me because I can say when I was there and I came home weekends then I didn’t take drugs...I just felt it won’t be nice to be in such a place and then take drugs] (Bolo)*

Bolo’s abstinence could be attributed to his fear of losing his place in the programme if he tested positive for substance use.

The Gateway programme focuses on interpersonal skills through its emphasis on learning in a group. Not all MHSUs are ready to socialise while in Gateway, preferring to seek social opportunities once they are back home and can control the amount of contact they initiate.

*“That was a learning curve because I think you are isolated and you mainly have your own thoughts and what you’re thinking is not quite right so going to Clubhouse and Gateway and Community Care Place gives you a first hand opportunity to experience the illness as others, learning from others and seeing it from this thing about you are not alone, we are not alone and they also have it...” (Mikaeel)*

Emmanuel has a long affiliation with Clubhouse and travels there to socialise and upskill himself.

*“I usually get my train to Clubhouse. I go there every Tuesday and Friday. I used to go every single day in 2002 and now only twice a week. It helps because of the facilities they have there, they give you driving lessons, catering, workshops like for making paper, wiring, all these things, admin unit where you do data capturing, all these things and answering the phone and secretary stuff. Then there is also some computer lessons as well... so that’s where I get to see the community. I see actually the people that are there in Clubhouse and where I get to gel with them and stuff.”*

As part of the pre-discharge programme at Gateway “the patient will be referred to the nearest community clinic and obtain at least one month’s supply from the clinic before discharge, as part of the reintegration

*programme*” (Associated Psychiatric Hospital, 2008). Gershwin refuses to attend the day hospital in his suburb, preferring to travel, at his own cost, to the Horizon hospital OPD department even though this is contrary to the PHC model or the Gateway policy document.

*“Unhappiness starts in 11th Avenue [suburb] day hospital. You wait there four, five, six hours; that’s with service and eight hours without service...or go to Horizon where you see a psychologist and psychiatrist and collect your medication at the dispensary, because it’s a lot faster than if you went to [suburb] day hospital...”(Gershwin)*

While in the Gateway programme *“patients will remain the outpatient of the specific specialist referral hospital”* as there is no psychiatric medication available at Gateway. Follow-up at Horizon hospital OPD is thus limited to Gateway inpatients during their three to nine month stay. During their time at Gateway, MHSUs develop a relationship with the OPD staff, which they are reluctant to terminate once they are discharged. They also perceive the OPD service as being more time-efficient than the CHC service. Like Gershwin, Mikaeel and Dan also collect their medication at Horizon hospital OPD. Through this, they illustrate that a one size for all policy directive does not meet individual needs.

During the study Emmanuel had to change CHC when his new address was updated on his folder. Although unhappy about the change, he acquiesced to it.

*“They called me yesterday when I was at the clinic because now I changed clinics. I used to be there 2012 so I came here in 2013 so they still had my folder. The sister who was attending to me she also didn’t want me to be there but she said I must go to the nearest clinic. So they referred me but I’ll know her when I see her.” (Emmanuel)*

The clinic is in a Cape Flats suburb close to the township in which he lives, but he still has to use public transport to get there. He does not know the mental health nurse at the new clinic and given that it is an integrated health

care system, he will collect his medication from the dispensary, making it unlikely that he will see her, unless he relapses.

In summary, this section presented findings to substantiate the second category 'There is no one size for all'. MHSUs view ongoing, known medical support as a mechanism to prevent relapse and possible hospitalisation. The PHC policy however, favours an integrated health service that is geographically convenient and based on the assumed needs of the collective, but where the service providers are unknown to the MHSU. This compromises the need for personalised care as identified by the MHSUs.

### **5.5 Category 3: 'It's tricky choosing between places to go and things to do'**

The findings reported in this category describe how every aspect of the participants' community life is impacted on by their mental disorder. The complexity of the choices MHSUs are faced with when attempting to integrate into their communities is described here. Their participation in occupations of choice promotes a sense of belonging and integration, but their options are severely constrained by structural elements and the contexts in which these occupations take place. These contexts put them at risk of relapse, but also holds the delicate possibility of preventing it.

*"As far as I'm concerned I am integrated. I'm not overreaching. I'm taking what I've got and trying to make the most of that. I'm not imagining being here or there, just taking what I've got. I would say it is basically getting along with and being part of something." (Mikaeel)*

Having a diagnosed mental illness is known to negatively affect the self-image and internal motivation of MHSUs. This leaves them struggling to undertake actions driven by their own interests and passion.

*"I have no purpose here, no purpose...lack of purpose is a bitch. It's something I wouldn't want to wish on anybody, lack of purpose. It's a real*

*bitch. I've got an immense amount of lack of purpose. You must understand it's stemming from a lot of things. I don't have a job, I'm classed with a mental illness, I don't feel like I'm at my prime physically the way I used to be, I did martial arts for 20 years and I was good, I had a girlfriend. All those things slipped away in my self-loathing, because I had no purpose."* (Gershwin)

MHSUs described that the limitations on their agency caused by external and personal factors impacts on their motivation to work towards achieving their goals and aspirations.

*"I just want to lead a life that I feel is right. By dating, by getting a job, by getting a place I need to be for me because I've been with them [his parents] ever since, under their roof. And how old am I now? 31...you see? It's kinda difficult because I will never learn to grow in that environment and now I'm lazy."* (Emmanuel)

MHSUs also expressed difficulties related to the temporal aspects of their community integration. This is illustrated in the sentiments expressed by Bolo and Emmanuel as to how, where and with whom they spend their time.

*"It's only when the day goes by and then maybe I have to face another day, especially not in the house, but go somewhere, but then I leave my house and go somewhere else. I leave my house because they are not supportive, especially my father."* (Emmanuel)

Bolo spends his time away from home, returning only to sleep. He became distressed when trying to explain the reasons why he does so.

*"Ek hardloop van die huis af...Ek hardloop net weg tot die aand toe en kom ek weer die aand huis toe." [I run away from the house... I just run away till the night and then I come home again at night.] "The environment, environment, environment I'm living in...I get blamed for stuff. Sometimes I do it but if I don't do it I get labelled you see and I don't think. They say I take things there at my home and sometimes it isn't me."* (Bolo)

Dan is required to leave the group home on weekday mornings and sometimes he attends a club frequented by other MHSUs, even if it means travelling to get there.

*“Chillout club, I go there whenever I have a day off from nine until twelve or one o’clock. What I do is I uhm, pretty much just sit and talk to the people that are there, we take part in different games and then we have coffee on the hour, every hour and I just wish that my friend Troy<sup>45</sup> could come and be a part of it but he doesn’t like to travel on the train every single day just to get there.”*

The catch-22 in this category is reflected in the dilemmas faced by MHSUs as they questioned the notion of integration into a society that does not accept them once they have been in a psychiatric facility. They often choose to keep their mental illness a secret in order to access opportunities for community integration.

*“There can be no such thing as successful integration unless you make it something that is hidden because there is no such thing as reintegration once you’ve been to a psychiatric facility. That is a separate part of your life. Because the point being that people are going to judge people always. And that’s going to stay...you can’t get away from that stigma. No your life stops once you go in.” (Gershwin)*

Since community members often hold discriminatory perceptions of MHSUs, participants negotiate disclosure and apply strategies to protect themselves.

*“I never say what eight or ten sentences into the conversation and then suddenly this person is my best friend and then I say to them, listen I have schizophrenia, or I have bipolar. That’s my own business I keep it to myself else I’m gonna get into a debate about what it is and I’m gonna have to defend it because that’s what you have to do.” (Gershwin)*

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<sup>45</sup> Pseudonym used.

Having neutral spaces, untainted by the diagnosis, in which to seek out human contact on a daily basis is important to MHSUs. In their day-to-day lives MHSUs determine which spaces are safe for disclosure.

*“Like I said, the people I know on the streets and shops have no idea, they just see a friendly guy and it’s important that people accept you and that they treat you like a normal guy, not like someone from outer space, that people accept you. Here for me I’d rather not disclose to people I see on a daily basis.” (Mikaeel)*

Limiting their disclosure allows MHSUs to meet their social needs and experience a sense of belonging even if others might judge these relationships as superficial.

*“Look, most of the people I do see and interact with are all working people, they’re selling the coffee, or doing the security...Most times it’s just like, just chitchat and chilling. I’ve come to see that as being meaningful in its own right even though it’s only an acquaintance, not deep relationships, or whatever but you know it’s good enough for me. It makes me feel good.” (Mikaeel)*

Having places to go to that allow him to “hang out” and “chitchat” facilitates Mikaeel’s sense of community integration. These places are varied but all are accessible and located fairly close to where he lives.

*“McDonalds in [Shopping mall]. I hang out there a lot. Ja, it’s pleasant. I go there for the coffee because it is the cheapest coffee in town. I sit outside and I chill. You know, watch people go by and I bump into a lot of people I know from family, friends, to psychiatric colleagues.” (Mikaeel)*

Being able to initiate when he wants to spend time on his own or with others (who have and who don’t have a mental illness) is how Mikaeel grades his socialisation. This promotes his sense of community integration.

MHSUs have to make choices related to the occupations they engage in at the places they frequent<sup>46</sup>. Emmanuel is a loner by nature but he seeks out social spaces to connect with others. In his township these spaces expose him to smoking and drinking.

*“There’s this guy, Brian, in our community, he’s a coloured guy...then I go to him then it’s kinda difficult as well because when I visit them they’re drinking and they’re smoking... Then here is a spaza<sup>47</sup> shop that I go to. But I have a problem with myself then I do things that I shouldn’t be doing, like smoking. But I’m trying not to, so this morning as I was coming here, I passed the shop to catch the taxi, without going in.” (Emmanuel)*

Being able to resist the temptation to smoke and drink through changing his routine is a strategy employed by Emmanuel to avoid exposure to his relapse triggers. For Dan his socialisation options become more limited because his relapse trigger is alcohol, which is readily available in the mainstream socialising spaces he frequents.

*“So I’m not allowed to drink any alcohol and what I do like doing is playing pool and I’m really good at it. Sometimes we go to the uhm, pubs and, and challenge the people to play pool. We do drink water and what happened on Saturday night we asked the bar lady if they have a jug of water and she said, no, no ways, this is an alcohol-drinking bar and you only come here to drink alcohol. So we walked out and decided not to play there... No, there aren’t pool tables with no alcohol... and like you can easily get influenced into drinking.” (Dan)*

Dan has to be firm in his decision not to abuse substances because he stands to lose his place in Safe House. The pervasiveness of alcohol and illicit substances is demonstrated in the following quote.

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<sup>46</sup> MHSUs are challenged by high rates of unemployment, violence and crime, medication non-compliance, poor social circumstances, poverty and mental disorders with co-occurring rates of substance abuse.

<sup>47</sup> Informal shop in township area.

*“In Ester<sup>48</sup> street there’s still a lot of drugs being dealt in Ocean View and the guy you could see was standing there with a whole packet of drugs, but like besides that, like also on Cape Town station there’s still a guy selling drugs there because I walked past there and he offered me drugs again and uhm, ja the dealers are still around.” (Dan)*

In order prevent a relapse, Dan limits his exposure to cash and is cautious of where he spends his free time. However these strategies limit the self-sufficiency and independence he strives for in his attempts to be integrated into his community.

Bolo is also faced with opportunities to gamble and abuse drugs and alcohol, but unlike Dan, he does not indicate a desire to stop. Using tik and gambling are pastimes that gives him a sense of purpose and improves his self-image.

*“What does it mean to feel getik?” (Fadia)*

*“It mean jy kan imagine, jy kan tokkies<sup>49</sup> vang, jy kan jokes maak, jy is powerful.” [It means you can imagine, you can catch tokkies, you can make jokes, you are powerful]” (Bolo)*

*“I’ll do anything for gambling. I’ll do anything for gambling. I’ll take my mother’s money, I’ll take my sister’s money, my grandma’s money, my auntie’s money, I’ll even take my uncle’s money, I’ll take my brother’s money, evens the baby’s money also” (Bolo)*

Having a mental disorder seems to imply that there are only particular kinds of work that MHSUs can do. Gershwin holds a tertiary qualification and applied for an administrative job but was offered a job that did not require these skills. He lamented this mismatch but took the opportunity to earn an income.

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<sup>48</sup> Pseudonym used.

<sup>49</sup> A tik-induced state of preoccupation used in Cape Town street youth culture to describe feeling both mentally absorbed while simultaneously being withdrawn and absent-minded (Reihling, 2011).

*“I applied for a job behind a desk working a computer. I said on my application that I can’t work outside, I got a mental disability and the other question was “Are you able to walk or run? Are you physically fit?” I answered them: “No”, because I’m not, and erm, they eventually contacted me back with a job and the job was everything except what I asked for. I was sweeping streets in the community, on the beach, cleaning up areas. It wasn’t difficult work; it was just hard work. Manual labour and, I was very grateful for the work, but it also showed me that I can’t work outside, I’m not very strong, I have a disability. It was all there. I was honest.”*

While there was a compromise between his occupational identity and his need for economic survival, his personal well-being was also jeopardised because of the way the public health service is structured.

*“Ok, currently I’m in a predicament. Two weeks ago I had to give blood for my lithium levels and I just chose not to go because I was working and that means I needed to get a day off and then I would need to be there at nine o’clock in the morning and then see my doctor at one o’clock and that was going to be a whole day thing and they were gonna do also a thyroid, take blood for thyroid and then I still have to pick up the medication... And the thing about it is if I don’t make contact, I haven’t and if I don’t make contact with them then there is procedures that they must follow...”*  
(Gershwin)

In the absence of an after hours clinic, Gershwin chose to miss his medical appointment instead of not attending work, fully aware of the health consequences of doing so. This incident reflects the catch-22 inherent in the choices MHSUs constantly have to make as they seek to engage in occupations, such as work, in a health system that is too rigid to accommodate this reality.

Lacking internal motivation is one of the negative symptoms of having a mental disorder. For Dan there is a desire to secure a job with a previous employer but he has not yet availed himself to the opportunity.

*“Uhm, the Navy. They promised me that they’d employ me now and then on a day’s work, just so long as I’m there at about half past seven.” (Dan)*

*“But they don’t contact you before the time?” (Fadia)*

*“No, they come out and call you.” (Dan)*

*“So in this month how many times have you gone?” (Fadia)*

*“I haven’t gone yet. I’ve been too busy but I’m going to go tomorrow morning.” (Dan)*

There is tension between work that is available and having the capacity or inclination to use the opportunities as they arise. While employment matters for all participants there are a variety of reasons why MHSUs struggle to pursue opportunities.

In summation, ‘It’s tricky choosing between places to go and things to do’ reflects important data on the inflexibility of structural elements, which frame personal occupational choices in the current environments of MHSUs.

## **5.6 Summary**

The findings described in this chapter illustrate the male MHSUs journey as they strive towards an independent community integrated life. The theme ‘It’s a catch-22 situation’ symbolises the flexibility needed by male MHSUs as they deal with the tensions created by different factors impacting on their lives and the range of strategies they employ to facilitate integrated community living. Some of these strategies are acquired, reinforced or eroded during participation in the inflexible step down/step up programme. Other strategies develop over many years of living and learning to cope with a serious mental disorder.

## **CHAPTER 6: DISCUSSION**

### **6.1 Introduction**

The findings revealed that the preparation for community integration of MHSUs through a step down/step up programme contrasted with the actual process experienced by MHSUs of becoming part of a community. The discussion highlights discrepancies between mental health policies, a residential-based rehabilitation programme in the Western Cape and the experiences of male MHSUs. It considers the implications of a residential-based rehabilitation programme located in a medical model of service delivery.

Through discussing the tensions revealed by the theme 'It's a catch-22 situation' the PHC approach to mental health care in its current form is problematised. The argument is made that the medical model alone is insufficient for community integration. The discussion promotes the alignment of policy and practice in the public mental health sector to the needs of MHSUs. More specifically, it is argued that mental health services need to allow MHSUs to co-construct their recovery journeys in order to be better prepared for community integration.

### **6.2 The gap in access to public mental health treatment**

South Africa's current public health system experiences obstacles such as racial and gender discrimination, income inequalities, health inequities and difficulties resulting from fragmented family life and persistent violence inherited from the apartheid era (Coovadia et al., 2009; Lund & Flisher, 2006; Mooney & McIntyre, 2008). Additionally the MHSUs in this study experienced stigma and discrimination, based on their psychiatric disabilities, which

intersected with their identities as men. Kohn et al., (2004) examined the worldwide treatment gap (World Health Organization, 2001b) between people needing treatment and those accessing mental health care. They focused on serious mental disorders and reviewed community-based epidemiological surveys related to service utilisation published since 1980. Although developing countries were underrepresented in their study, they found that for schizophrenia, the most severe mental disorder, at least one third of people remained untreated. They concluded that relevant policies, programmes and service developments are needed to close the treatment gap. A consideration of this perspective in relation to the Western Cape Metropole area now follows.

### **6.3 Access to mental health treatment in PHC services**

The PHC service model currently being implemented by the step down/step up facility focuses on the *“provision of accessible and comprehensive services close to where people live”* (Western Cape Department of Health, 2014, p.28). These PHC principles are based on the assumption that devolution of services to CHCs would decrease travel time, be more convenient, accessible, appropriate and desirable for MHSUs. The community integration scenarios shared by the five MHSUs in this study challenge this assumption. MHSUs experience the integrated services as impersonal, unstable and unfamiliar and not advancing their sense of community integration.

MHSUs preferred accessing services where they knew the mental health practitioner even if it meant going back to the OPD of the psychiatric hospital. Travelling to mental health services was built into their lives and was a way for them to manage their illness identity. Devolution of care to an unfamiliar clinic does not work for everyone. The current design of the PHC service does not provide for the relational link that MHSUs in this study valued with their service provider. They placed as much emphasis on the relationship as

on the medication needed to support recovery. While some MHSUs in this study complied with the system which required them to collect their medication at their local CHC, others chose to defy the system and accessed a service that they were comfortable with. A number of studies confirm the need for stable service providers in the recovery journey of MHSUs (Howe, Tickle, & Brown, 2014; Sutton, Hocking, & Smythe, 2012; Tew et al., 2011).

One way to address the relational dimension of community integration is through creating links with ACT team members to anchor MHSUs when they are discharged back into their communities. This will allow for continuity of care so that MHSUs do not 'get lost' in the integrated system (van Vugt, Kroon, Delespaul, & Mulder, 2012). The value of the ACT team is emphasised in the study by Tempier, Balbuena, Garety and Craig (2012) who reported that support offered via an ACT team improved clinical outcomes because it assisted MHSUs in re-establishing bonds with family, friends and acquaintances. The multidisciplinary ACT model of care, through its assertive, individualised and intensive services, is known to reduce hospitalisation of MHSUs but its impact on quality of life and well-being is underresearched (Botha et al., 2010; Krupa et al., 2003).

While the ACT teams within the APH group are focused on symptom reduction through medication adherence and support through home visits, it remains a challenge for them to expand the team to include occupational therapists. Occupational therapists on ACT teams are able to contribute towards understanding the relationship between occupational performance, mental illness and adjustment to community life (Cook et al., 2009; Krupa et al., 2003).

Although mental health has been integrated into general health care in the Western Cape, this is translated into the accessibility of psychotropic medication at CHC level. Inequalities in the mental health service platform in terms of resource allocation and staffing remain (Coovadia et al., 2009; Draper et al., 2009; Mayosi et al., 2012). MHSUs in this study shared the view that only collecting medication from a dispensary was insufficient because it did not allow for the relational dimension of community integration.

They were also dissatisfied with the long waiting times associated with CHCs. Although there have been studies reporting on the inconsistent availability of psychotropic medication at primary levels of care (Kakuma et al., 2010; Petersen et al., 2011), none of the MHSUs in this study complained about inconsistencies in receiving their prescribed medication. However, one MHSU highlighted the difficulty of having a mental disorder along with another medical condition. He collected his TB medication from one clinic and his psychotropic medication from another, so in his case the medication needed to maintain his health, was not available at a central point.

#### **6.4 Mental Health promotion for community integration**

Mental health impacts on human and social development (Chisholm et al., 2007; Lund et al., 2011; Petersen, Bhana, & Swartz, 2012; Prince et al., 2007). Equally, social, economic and physical environments shape mental health and social inequities are risk factors for mental disorders (Cutchin et al., 2008; Galheigo, 2011; Weisser, Morrow, & Jamer, 2011). The men in this study considered themselves to be recovered and partially integrated in their communities. In the absence of regular employment, their main source of income was social grants. For some, petty crime, substance abuse, interaction with law enforcement and living with stigma and discrimination were part of their day-to-day existence. Their occupational choices were entangled in the adverse contexts in which they found themselves.

A social determinants of health approach (World Health Organization & Calouste Gulbenkian Foundation, 2014) to mental health requires collaboration between different levels and sectors of government and society. This approach acknowledges that risk and protective factors include the individual, the family, the community, the structural and the population levels. Given the legacy of apartheid in South Africa where deep-rooted poverty, violence and social inequities persist (Blas & Kurup, 2010; Mayosi et

al., 2012; Venkatapuram, 2010), alternative ways to promote mental health and promote peace and inclusion of the whole community are needed.

While Petersen et al. (2012) point out that South Africa has mental health promotion policies that address the mental health needs of its citizens across the life span, they acknowledge that interventions promoting well-being of vulnerable populations are underdeveloped. They recommend that interventions should address poverty alleviation, gender equity, social redress, health promotion, interpersonal violence and sustainable livelihood development. The study findings confirm that the social gains that can be reached through such interventions are not a reality for MHSUs. None of the men reported awareness of public sector mental health promotion initiatives in their local communities. Wilcock (2006) contends that it is motivation and behaviour of individuals and communities that influences health promotion initiatives. The question that arises here is to what extent the motivation and behaviour of MHSUs are mediated by the kinds of environments in which they live, socialise and seek employment.

While the NPO sector provided support networks to MHSUs, only two such NPOs were mentioned and both were geographically located in previously white areas. MHSUs did not mind travelling to the NPOs because they were recovery-focused and addressed their community integration needs in terms of occupation, social support and assimilation (Weisser et al., 2011; Yanos, 2007). In light of this, contextually relevant programmes based on an understanding of the local issues affecting MHSUs need to be developed.

#### **6.4.1 Shift of care from institutions to community-based services**

The introduction of the residential-based rehabilitation service in 2008 addressed the need to shift services from institution to community-based care (Faydi et al., 2011; Kleintjes et al., 2008). The men in the current study viewed the residential-based rehabilitation programme as an extension of their hospital admission because of its inflexible structure. Their programme

routines were disconnected from their community routines and did not prepare them for the practicalities of their lives once discharged. Additionally, Gateway is located in an affluent area, far from where participants reside. Its location contradicts the Healthcare 2030 policy intention to provide community-based services close to where service users live. While its value as a respite space that separated MHSUs from their stressors was acknowledged, the opportunity to help the men prepare for their integration back into their communities was not sufficiently addressed in the key elements of the programme. While the literature affirms the importance of resting and reflection places, researchers also propose that respite and reflection time should be followed up by opportunities to engage in the everyday world in order to facilitate the MHSUs re-engagement in life with what matters (Sutton et al., 2012; Tew et al., 2011)

The rehabilitation services offered through the Gateway programme are focused on psycho-education and social skills training which follow a predetermined course. Jivanjee et al. (2008) found that having a sense of personal control is central to MHSUs' vision of successful recovery which manifests as an individually defined 'successful community life'. The MHSUs were not offered the choice to engage in personally relevant, community-orientated occupations while in the programme. Some programme content did not have immediate relevance to their community integration and did not make sense to them when they were in the programme. Once they were in their communities, when they were ready to engage with aspects of the programme content, it was no longer available to them. Jivanjee et al. (2008, p.415) recommend a hybrid community-based programme focused on collaborative, continuous and comprehensive services to meet the changing needs of MHSUs across their lifespan.

The findings revealed a mismatch between what the programme offers, how staff promote the content and how the MHSUs use and apply the content. Bridging is an enabling process if it considers the different parts that need to be bridged in order to facilitate community integration (Davidson & White, 2007; Farkas, 2007; Tew et al., 2011; Venkatapuram, 2010). For the MHSUs

in this study, bridging opportunities did not occur and they independently navigated their community integration.

Manuel, Hinterland, Conover and Herman (2012) recommend that service providers ease the transition from institution to community by discussing MHSUs' options for community living and treatment as well as acknowledge their identity transition from inpatient to ex-patient. This will give them latitude in their transition to independent action. In the current study the inflexible programme did not sufficiently consider the barriers faced by MHSUs as they tried to participate in society nor did it allow for independent action (Gibson et al., 2011; Kelly et al., 2010; Sutton et al., 2012).

The content of the step down/step up programme is constructed around participation in a group and is informed by a medical model of care, which looks at symptom reduction and not CBR (Kramers-Olen, 2014; Petersen & Lund, 2011). Involving MHSUs in constructing personally relevant recovery plans will align the content of the programme more to what is needed in terms of their personal community integration (Eklund & Hansson, 2007; Kramers-Olen, 2014; Macpherson & Gregory, 2007; Schofield, 2006). MHSUs need service settings to be flexible to accommodate their personal goals (such as work) while still helping them access treatment. There is an opportunity for rehabilitation services to create partnerships and spaces for dialogue, which will promote social functioning and respect diversity amongst MHSUs through aligning the structure and content of the programme with MHSUs' needs (Farkas, 2008; Slade, 2009)

It is argued that a medical model focus is thus insufficient to promote well-being and community integration for MHSUs (Adame & Knudson, 2007; Corring & Cook, 2006; Frese, Knight, & Saks, 2009; Nelson, Lord, & Ochocka, 2001; Swartz, 2014; Townsend, 2012; White, 2010; Wilcock, 2007). In this study, MHSUs were unanimous that they did not carry their illness identity with them, yet it was the key identifier for service providers and their families in terms of gauging their potential for recovery. This labelling creates tension since the diagnosis allows them to access treatment

but the diagnosis is also a source of stigma and social exclusion (Dinos, 2014; Happell, 2007; Howe et al., 2014).

For the MHSUs trying to navigate their community integration in this study it can be argued that it is society that disables them through stigma, social exclusion and discriminatory practices which do not allow for their full participation and equalisation of opportunities as MHSUs (Hammell, 2006; Heap, Lorenzo, & Thomas, 2009; Siyabulela & Duncan, 2006; Swartz, 2014; Tew et al., 2011). The contexts in which discriminatory practices were found included the individual (self stigma), social, cultural and political realities (Frese et al., 2009; Happell, 2007; Lafrance & McKenzie-Mohr, 2013; Prince et al., 2007).

As evidenced in this study, while MHSUs needs were met in terms of access to medication; their social and vocational needs were not met while in the programme or within their communities. None of the men were permanently employed at the time of the research, none were living on their own, none were in long-term relationships and none had children. They lived in areas across the Cape Flats and their access to resources did not include services outside of the health-related ones available to them by virtue of their diagnosis (Ataguba, Akazili, & McIntyre, 2011; Chisholm et al., 2007; Jacobson & Greenley, 2001; Prince et al., 2007; Weisser et al., 2011).

#### **6.4.2 Mental health literacy for social inclusion**

Mental health awareness and literacy should be integrated into health and social policy in order to combat human rights violations, stigma and discrimination at all levels (Dinos, 2014; Kakuma, Kleintjes, & Lund, 2010; Prince et al., 2007; Slade, 2009). The men in this study reported their reluctance to disclose their mental illness to people they met for fear of stigma, discrimination and social exclusion. This need to assimilate is an aspect of community integration that MHSUs navigated on a daily basis, as they sought opportunities to conform and be accepted in society as people

first and not as MHSUs. Improving the mental health literacy of families, communities and service providers can decrease the stigma associated with severe mental disorders, and can improve the likelihood of MHSUs disclosing their status without fear of discrimination. In this way the divide between professional and public knowledge about mental disorders can be decreased (Coles, Coleman, & Heimberg, 2008; Dinos, 2014; Kelly, Jorm, & Wright, 2007).

Mental health literacy should be provided through a multisectoral, collaborative approach involving a wide range of service users, caregivers, advocacy, policy, service delivery and research organisations (Coles et al., 2008; Kelly et al., 2007). In this study men experienced their involuntary psychiatric hospital admission at the hands of the police as violent and in violation of their human rights (Choe, Teplin, & Abram, 2008; Jacobson, 2001). This abusive experience, coupled with the restrictive nature of the acute admission setting, led to MHSUs likening their hospitalisation experience to imprisonment. Another aspect impacting on community integration is the distrust of the health system, which causes MHSUs to delay seeking help and to avoid hospitalisation (Dinos, 2014; Howe et al., 2014; Wisdom, Saedi, Weis, & Green, 2008).

Addressing the attitudes of professionals and the general public to MHSUs will reduce stigma, encourage help-seeking behaviour and foster community inclusion (Dinos, 2014; Frese et al., 2009; Howe et al., 2014).

#### **6.4.3 Advocacy, policy-making and self-help initiatives**

South African policy and legislation advocate a human rights approach to community-based mental health services (Kakuma et al., 2010; Kleintjes et al., 2010; Petersen & Lund, 2011; Petersen et al., 2011). An opportunity arises for MHSUs to contribute to the development and implementation of relevant mental health policies (Kleintjes & Lund, 2010) that are more aligned to the need for personally co-constructed care plans. While there is support

for consumer involvement, strategies to action this are needed. The inclusion of MHSUs in the development of policies will convey acceptance that they have the right to participate in decisions which influence their lives (Burgess, 2014; Heap et al., 2009; Kleintjes & Lund, 2010).

Adopting a CBR approach (Lorenzo, 2003; World Health Organization, 2010), which includes intersectoral collaborations, could further the opportunities for MHSUs to be integrated into their communities. The men's experience of community integration revealed that aspects related to mental health promotion, prevention and rehabilitation were not personal enough to meet their individual needs. They had recovery needs that spanned their living, working and social environments and they were forthcoming about what did and did not work at the PHC, institution and at the intermediate level of care.

Attempts at addressing the invisibility of disability has been created through deinstitutionalisation, the creation of community-based care, health promotion and prevention strategies and consumer involvement in policy development. These strategies are all geared towards helping marginalised people access their right to human dignity (Galheigo, 2011; Kakuma et al., 2010; Kleintjes et al., 2013). While the step down/step up programme helped MHSUs learn about their rights and responsibilities as citizens, family members and workers, it did not create spaces or continuity opportunities to exercise these rights once discharged.

In summary, this section discussed the findings in relation to the first four recommendations as suggested in the World Health Report (World Health Organization, 2001b). It highlighted the discrepancies between public health policy intentions and the services offered to MHSUs, and argued that public health planners should attend to the treatment gap between medical services and resources and interventions that promote recovery (Boesten, Mdee, & Cleaver, 2011; Burgess, 2014; Petersen et al., 2012).

## **6.5 Occupation-based practice for community integration**

According to Wilcock (2006) people experience well-being when they are able to engage in occupations they need to or want to do, in an environment which allows it and when they have the physical, mental and social support to do so. The well-being of the men in this study was compromised as they were often frustrated in finding meaningful occupations, were not living independently and did not have the necessary social support from service providers or others to advance their well-being (Davidson & White, 2007; White, 2007). Given their positionality it could also be argued that their occupational choices were limited because of the prevailing historical, socio-economic and political factors impacting on their choices (Galvaan, 2015). This was evidenced in their choice to access social networks which did not always promote their health and well-being. While the element of pooling for mutual benefit was present, some MHSUs engaged in behaviours and occupations such as smoking, gambling, stealing and abusing substances which often led to physical harm, loss of financial resources and accommodation and relapse (Krupa et al., 2009; Townsend, 2012).

Coleridge (1993 in Hammell, 2004, p.299) suggested that the quest for meaning has intrinsic, spiritual, political, social and economic dimensions which influences people's ability to exert meaningful control over their lives. In order to foreground occupation, mental health programmes need to be aligned to the realities of where people come from, where they are going and what they do and aspire to do. Yanos (2007) recommends studying the influence of place (mental health geography) on the social inclusion and exclusion of mental health service users.

Apartheid South Africa divided people along racial lines with geographical consequences which privileged some and disadvantaged others. The experience of place impacts on individual and occupational interactions (Townley et al., 2009). The findings suggest that the social and physical environments faced by the men in the study put them at risk of relapse. Examples of these were the lack of alcohol-free recreational spaces and the

ready availability of illicit substances in their communities. MHSUs who accessed NPO services felt that their mental health needs were being met and this helped them resist engaging in occupations that put them at risk.

Occupational disruptions are a result of health conditions or social circumstances, which disturb a person's ability to engage or benefit from occupations (Krupa et al., 2009). Admission to Gateway was both a health necessity and an occupational disruption in that it interfered with MHSUs' abilities to participate in, and benefit from self-directed occupations. The study participants reported that Gateway's primary function was respite from the demands of daily life and the promotion of social cohesion amongst participants (Blas & Kurup, 2010; Davidson, 2007; Sutton et al., 2012; World Health Organization, 2001). Planned interventions within the programme did not always address the other benefits of occupation such as normalisation, routine, skill acquisition, purpose, competence productivity and pleasure because it did not have personal meaning to the MHSUs expected to engage in it (Hammell, 2004). In order to experience this set of benefits from occupational engagement, the programme requires flexibility and creativity with due consideration to the roles of position, space and place that each MHSU occupies beyond the confines of the institution.

Support for MHSUs in different states of engagement is needed in order to accept their self-regulated involvement in the world. Aligned with the findings of Sutton et al. (2012), this study revealed how MHSUs self regulate their level of engagement in everyday activities and in so doing, perceived themselves as 'community integrated', although not as fully as they would have liked. Social connections are made when and where it suits their need to assimilate in different contexts. However, their community integration is viewed by society and service providers as consisting of superficial connections and social isolation, yet the findings suggest that even superficial engagement in occupations with others can affirm a sense of being and belonging (Sutton et al., 2012). Participants chose to routinely frequent public spaces, which allowed minimal interaction with others, while still allowing for participation in public life.

The evidence suggests that MHSUs are obligated to participate in the step down/step up programme even if they do not see value in the interventions offered. Clearer links are needed between residential and community-based occupational engagement. MHSUs promote personal recovery and facilitate community integration on their own terms. They need a residential-based programme that affords them gradual, graded exposure to community integration to develop a personalised recognition of what occupation-centred recovery could mean for them.

The MHSUs in this study reported idiosyncratic ways of reviewing the consequences of their mental illness. Each one made sense of his illness by finding meaning through the occupations they engaged in on a daily basis. Some were located in routine patterns of behaviour, while others responded to their needs on a day-to-day basis. Focusing on occupational engagement and helping MHSUs organize their daily occupations should be an important aspect of mental health services (Aldrich, 2008; Cook et al., 2009; Kelly et al., 2010; Sutton et al., 2012). As the findings suggest, current mental health services are limited in terms of intersectoral collaborations and do not favour an occupational perspective on health nor do services sufficiently consider where MHSUs come from or where they aspire to go and how context and environment influence their occupations and therefore their recovery.

### **6.5.1 Community integration through work occupations**

Having access to work has meaning for MHSUs in terms of their personal identity, well-being and sense of community integration. All the men in this study were unemployed and their primary source of income was via their monthly social security grant (disability grant) of ZAR1350. While social grants are the South African government's most widely used poverty alleviation strategy, there is growing recognition that this form of social security is insufficient to meet people's basic needs (Barrientos, Møller, Saboia, Lloyd-Sherlock, & Mase, 2013; Coovadia et al., 2009; Heap et al.,

2009; Kleintjes et al., 2013). Studies on the burden of chronic poverty and psychiatric disability found that socioeconomic position more than psychiatric disability dominated participants' existence (Duncan, Swartz, & Kathard, 2011a, 2011b; Gouws et al., 2010). While MHSUs desire work they also face barriers related to securing employment. The high involuntary unemployment rate in South Africa means that men in this study had to contend with the burden of unemployment as well social exclusion caused by their psychiatric disability (Kleintjes et al., 2013; Lund et al., 2010).

The residential-based rehabilitation programme focused on the administrative aspects of finding a job such as drafting a CV and securing an interview, but it did not address the realities MHSUs faced when they tried to access work opportunities. These realities ranged from having an erratic work history, to being employed in jobs not aligned to their skillset, as well as accessing piecemeal employment opportunities on a day-to-day basis (Davidson et al., 2001; Dunn, Wewiorski, & Rogers, 2008; Morrow, Wasik, Cohen, & Perry, 2009). Given that participants were in the programme for three to nine months, they expected graded re-entry into living, socialising and working spaces to facilitate their community integration but the generic nature of the programme did not address these needs adequately.

Even when they are able to work, the system does not facilitate supported employment (Baron, 2007; Jivanjee et al., 2008; Kramers-Olen, 2014; Won & Solomon, 2002). If their identity is constructed through the occupations they engage in (Carless & Douglas, 2008; Mee, Sumsion, & Craik, 2004; Topor, Borg, Di Girolamo, & Davidson, 2009), and work is one of these valued occupations, then being unable to work breeds feelings of failure. For those who worked, there was an additional dilemma related to collecting their medication during working hours and having to forfeit a day's work in order to do so, since there is no after-hours clinic available for the collection of medication. This shows a lack of appreciation for the many different kinds of employment options MHSUs engage in in the daily community lives.

In order to combat a sense of failure, the men sought any work opportunities, irrespective of whether they were ad hoc, voluntary or socially acceptable.

Work helps MHSUs develop a positive worker identity and feel accepted by others, and creates a sense of belonging (van Niekerk, 2009). Offering MHSUs different forms of employment support is thus an important dimension of community integration (Dunn et al., 2008; Eklund & Leufstadius, 2007; Morrow et al., 2009; van Niekerk et al., 2011).

Roberts and Wolfson (2004) advocate mental health services to develop supported employment schemes because of the role that employment plays in recovery through its financial, social, existential and spiritual benefits. The men in the study all accessed the NPO services at some point in their recovery journeys. NPOs provided a range of voluntary work options including skills-based training, practical projects and socialisation opportunities.

## **6.6 A recovery-based vision for residential-based facilities**

Slade's (2009) constructivist view of recovery calls for the co-construction of knowledge based on individual perception and social experience. The males in this study considered themselves to be recovered and integrated into their communities although it was not to the degree that they aspired to. Their community integration was more to do with how they personally renegotiated their community entry, and less to do with how the step down/step up programme promoted recovery. Understanding the multifaceted nature of community integration will guide clinicians involved in designing rehabilitation programmes that promote recovery (Eklund & Leufstadius, 2007; Eklund, Hermansson, & Håkansson, 2012; Kramers-Olen, 2014).

A transactional view of occupations (Cutchin et al., 2008; Davidson, 2007; Davidson & White, 2007; Farnworth & Muñoz, 2009; Sutton et al., 2012; Swartz, 2002) considers the interactions of daily life as a vehicle through which recovery takes place. The transactions that operate during occupation are influenced, in part, by intersectional identities including gender, race and sexual orientation. The men strategically improvised their habits and routines

in response to past experiences of being stigmatised and what was offered in the community. Central to this was the way they sought to affirm their role as men (Jewkes et al., 2009; Morrell, 2007). For some, priority occupations were aligned with their aspirations of having a job, getting married and having a family of their own. For others it was about belonging even if it was associated with gangsters in their communities. Recovery theory suggests that MHSUs consider themselves to be recovered when they are living a meaningful life, have a positive sense of self and have a sense of hope and self-determination (Bradshaw, Armour, & Roseborough, 2007; Farkas, Gagne, Anthony, & Chamberlin, 2005; Farkas, 2007, 2008; Kelly et al., 2010; Slade, 2009; Sutton et al., 2012).

The findings indicate that recovery is a personal, on-going, dynamic and life-course quest that starts with the first illness episode and continues over the years. The aim of service providers should be to increase MHSUs' social capital and empower them to have full citizenship in society (Farkas et al., 2005; Farkas, 2007; Kirsh & Cockburn, 2009; Roberts & Wolfson, 2004). Collaboration between service users and service providers is key to successful recovery.

The interventions offered to MHSUs while in the residential-based rehabilitation programme are located within the theories of psychosocial rehabilitation and recovery. To make good on these intentions the programme focus should be to co-construct the programme to support the MHSUs' recovery goals while in the programme and once discharged, given the social and structural dimensions which are central to recovery but which occur outside of the service setting. These include but are not limited to income, employment, living circumstances and social interactions (Vanderkinderen, Roets, & Van Hove, 2014). There are different paths to recovery and while evidence-based practice helps service providers monitor intervention outcomes these interventions must still be personalised. An appreciation of the recovery climate which promotes collaboration challenges service providers to work directly with MHSUs as well as to work developmentally with families and communities (Spaniol, 2012; Tew et al., 2011).

The research data suggests that MHSUs want to be seen as people with talents and abilities and not just as a MHSU with deficits as a result of their mental illness (Davidson et al., 2001; Gulcur et al., 2007; Iwasaki, Coyle, & Shank, 2010; Manuel et al., 2012). The findings of this study suggest that MHSUs would like to be involved in the planning of relevant services. The disability sector has a slogan “Nothing about us without us” and this speaks to the necessity of consumer involvement in service provision (Jivanjee et al., 2008; Kleintjes et al., 2013; Slade, 2009).

Gibson et al. (2011) found through their systematic review on occupational therapy interventions for recovery that the skills needed for community integration are activities of daily living, social participation, leisure, life skills training, physical activity, work and education. They advocate for occupational therapists to use this data and create networks across academic, professional and clinical staff so as to effect change in practice, research and education. Engaging in community mapping would help mental health practitioners to consider relevant stakeholders, resources cross-department collaboration opportunities (Mathie & Cunningham, 2003; Ross & Coleman, 2000; Slade, 2010b; Swartz, 2014; Townley et al., 2009; van Niekerk et al., 2011). However, Gibson et al (2011) do not address the ‘street smartness’ of MHSUs as a starting point for community integration networks, inferring rather that networks need to be created by formal structures. MHSUs develop ‘street smart’ skills from living with a mental illness for a number of years, which help them access community support in order to meet their goals.

Independence and self-actualisation opportunities in supported housing was another dimension of successful community integration found in the Gulcur et al. study (2007). The data confirms this through the stories offered by participants living in group homes. They held a level of independence while still being able to access support in their living environment. Dorvil, Morin, Beaulieu and Robert (2005) explored housing as an integrating factor for people living with a mental illness. They found that supported housing meant a range of things to their participants. These included: housing as a reflection of themselves; housing as an indicator of the severity of the illness; housing

as a coping mechanism; housing as a judgement free zone; housing as a physical space; housing as a relational space; housing as a connector to external support; housing that affords access to money and work; and housing as a connector to psychiatric services. The male MHSUs in the study who were residents of group homes echoed the findings in the Dorvil et al. (2005) study. Hearing MHSU experiences will guide the development of more relevant supported housing services.

## **6.7 Summary**

This chapter discussed the evidence of disjunctions in mental health practice between policy directives and service uptake by MHSUs during their recovery journeys. It also expanded on the continuity of care and the readiness of MHSUs, their service providers, carers and the community to recognise that recovery is an ongoing, non-linear journey. To this end the case for individualised community integration is argued, bearing in mind that the gender specific needs for occupations that promote health and well-being amongst MHSUs needs to be considered.

Health system transformation requires strategies that link a public-health model with individual care. As is evidenced in the findings, recovery is an ongoing personal process that happens in a specific community context. Public health services adopting a recovery-based vision will need to consider a continuum of services, which promote recovery goals such as housing, education, employment and social support. A long-term network of supporters are needed to facilitate this. These supporters include clinicians, family, community members and peers.

While the benefit for MHSUs of the step down/step up facility are clear in terms of its respite potential, its role as an intermediary between institution and community life that seeks to facilitate community integration for MHSUs, is nebulously defined and largely ineffective in practice.

# **CHAPTER 7: RECOMMENDATIONS, LIMITATIONS AND CONCLUSION**

## **7.1 Recommendations**

This chapter concludes the research report by summarising the recommendations for practice and research addressed in the discussion, noting the study limitations and making summative comments.

### **7.1.1 Recommendations for practice: step down/step up programme**

- It is recommended that the step down/step up programme consider the following:
  - o Service providers at the step down/step up programme should reorient their interventions to offer MHSUs opportunities to engage in occupations that are personally relevant to their community integration.
  - o Allowing MHCUs to access the step-up route to intermediate care if community living is proving too taxing. This is a mechanism to provide support for MHCUs in their non-linear recovery journeys.
  - o Developing a greater understanding of the diverse communities that MHSUs come from and the social challenges they face. This will require the programme to be flexible in accommodating differences and supporting integration into community life.

- o Playing a more active and realistic role in helping MHSUs develop and organise their daily occupations. The provision of opportunities for engagement in occupations that meet their personal needs and are based on their lived experience will assist MHSUs to reconnect with routines in their everyday life. While this is not limited to employment options it does require the step down/step up programme to support those MHSUs who have work to maintain their employment as well as advocate the right of all MHSUs to have access to work opportunities.

### **7.1.2 Recommendations for practice: service platform**

- The inclusion of occupational therapists on the ACT team will create opportunities to introduce an occupational perspective on health and well-being and other aspects of the occupational human.
- Community integration is a multidimensional concept. Its promotion cannot be restricted to health services. Intersectoral collaboration across government departments and community organisations is required to advance integration opportunities for MHSUs. An alignment of the CBR ideals with service delivery can be achieved through the extension of the PHC. This will allow for intersectoral positioning of services, partnerships with others and task-shifting opportunities.
- This research highlighted the contribution of nurses and doctors at PHC levels of care. There is another cadre of staff, rehabilitation care workers (RCWs), who can offer the long-term relational support valued by MHSUs in this study.
- Healthcare 2030 is the policy for the transformation of the public health service in the Western Cape. It would be of value to foreground

its emphasis on well-being and the life course approach to person-centred care. Mental health services need to move beyond their current focus on symptom reduction and medication compliance, and look at the socio-economic and political factors that impact on the well-being of the whole person.

### **7.1.3 Recommendations for research**

- The experiences of service users accessing public mental health facilities needs to be explored. It would be of value to compare MHSUs' understanding of community integration with those of service providers.
- Understanding the community integration of women would generate knowledge on the different ways in which community integration occurs on the basis of gender.
- Mental health practitioners need to familiarise themselves with the contexts from which MHSUs come and to which they are likely to return. This understanding of context can be aided through the development of resource maps (see 3.7.2). Resource mapping allows for a focus on more than just the CHC for medication follow-up but also on all the places and spaces which help or hinder personalised community integration.

## **7.2 Limitations**

Participants in the study who were first language Xhosa speakers had to speak in either English or Afrikaans. One participant was Xhosa speaking but he was schooled in English so he was comfortable speaking English during the interviews.

The residential-based rehabilitation service is not an established one and as such the programme content is still developing. This research informs the way that it can continue to develop.

### **7.3 Conclusion**

This research report has confirmed that the community integration of male MHSUs in this study was multidimensional and unique to each person concerned. The men's experience of community integration revealed that their transactions with contextual and socio-economic factors constrained their occupational choices. Even though they experienced varying degrees of success and satisfaction in their environments of living, learning, working and socialising they all considered themselves to be integrated into their communities.

Promoting personal recovery requires service providers to listen to what MHSUs aspire for in their lives. Current residential-based rehabilitation services operate within a medical model framework with a focus on the treatment of symptomatology. In the maelstrom of daily life, MHSUs view recovery as a subjective, uniquely personal lifelong process connected more to 'just doing life,' than with having a mental disorder. MHSUs view managing their mental illness as only one part of their identity, while others used it as the key definer of who they are. The medical management of the mental disorder is therefore not sufficiently recovery-oriented.

MHSUs acknowledge the benefits of the step down/step up facility as a respite space and as part of their clinical recovery. However, they query the programme ethos, which fosters dependence and limits their sense of agency. An admission requires them to forfeit goals in other areas of their lives as well as relinquish opportunities to engage in personally meaningful occupations of their choosing. While it could be considered that the MHSUs are not integrated into their communities because they are not living

independently, it can be contested that independence is a Western aspiration and that their mental disorder necessitates interdependence.

Community integration cannot be directed by mental health programmes that pull MHSUs away from the community and into protected mental health services and settings. Rather it is part of the process of recovery in the real world, aligned to the particular experiences of the MHCUs that can facilitate community integration. MHSU perspectives on community integration indicates that they will be better prepared for the nuanced nature of living in the outside world if the key elements of the residential-based rehabilitation programme allows them to co-construct their personal recovery plans.

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# APPENDICES

## Appendix A Literature Search

I conducted a literature search bearing the question: “ Does admission to a step up/ down facility decrease the chances of relapse compared to direct discharge from psychiatric hospitals for mental health service users?” in mind.

I searched the following databases: EBSCO host ,Cinahl, Pscyinfo, Psychlit, ERIC, Medline, Pubmed, Cochrane library and Web of Science.

The search terms used were: Step up/ down facilities, supported housing, transitional living, halfway houses , Assertive community teams, community mental health teams, sub-acute care, (supp\* Accom\* , comm\*), Hospital care, residential care, day hospital care, mental health service users, psychiatric disabilities, psych\*, severe mental disorders, Adults, Schiz\*,Service utilisation, relapse, readmission, programme evaluation, treatment, mental state, quality of life, community integration, social functioning.

There were 41000 hits, which were reduced to 21000 by reducing the publication date to the period 2000-2014. There were 4255 full text articles and 118 clinical trials and systematic reviews. I read all the abstracts and narrowed it down to 25 articles.

The literature search yielded no direct consensus on what was being advocated for in terms of preferred models of community mental health service delivery.

## Appendix B UCT Human Research Ethics Approval



UNIVERSITY OF CAPE TOWN  
Faculty of Health Sciences  
Human Research Ethics Committee



Room E52-24 Old Main Building  
Grote Schuur Hospital  
Observatory 7925  
Telephone [021] 406 6338 • Facsimile [021] 406 6411  
Email: [linsey.samuels@uct.ac.za](mailto:linsey.samuels@uct.ac.za)  
Website: [www.health.uct.ac.za/research/humanethics/forms](http://www.health.uct.ac.za/research/humanethics/forms)

26 September 2013

**HREC REF: 582/2013**

**A/Prof EM Duncan**  
Health and Rehab Sciences  
F46  
OMB

Dear A/Prof Duncan

**PROJECT TITLE: COMMUNITY INTEGRATION OF MALE MENTAL HEALTH CARE USERS FOLLOWING PARTICIPATION IN A RESIDENTIAL BASED REHABILITATION PROGRAMME**

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee for review.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

**Approval is granted for one year until the 30<sup>th</sup> September 2014**

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period. (Forms can be found on our website: [www.health.uct.ac.za/research/humanethics/forms](http://www.health.uct.ac.za/research/humanethics/forms))

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

**Please quote the HREC reference no in all your correspondence.**

Yours sincerely

PP *TuBurgess*

**PROFESSOR M BLOCKMAN**  
**CHAIRPERSON, FHS HUMAN ETHICS**

Federal Wide Assurance Number: FWA00001637.

Institutional Review Board (IRB) number: IRB00001938

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP) and Declaration of Helsinki guidelines.

The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

## Appendix C Western Cape Government Ethics Approval

RP 156/2013



**STRATEGY & HEALTH SUPPORT**  
Health.Research@westerncape.gov.za  
tel: +27 21 483 6857; fax: +27 21 483 9895  
5<sup>th</sup> Floor, Norton Rose House,, 8 Riebeeck Street, Cape Town, 8001  
[www.capegateway.gov.za](http://www.capegateway.gov.za)

REFERENCE: RP 156 /2013  
ENQUIRIES: Ms Charlene Roderick

**Department of Health & Rehabilitation Sciences**  
**Division of Occupational Therapy**  
**F45 Old Main Building**  
**Groote Schuur Hospital**  
**Observatory**  
**7925**

For attention: **Prof EM Duncan, Prof R Galvaan and Ms F Gamielidien**

**Re: Community integration of male mental health care service users following participation in a residential based rehabilitation programme**

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research.

Please contact the following people to assist you with any further enquiries in accessing the following sites:

**Hospital**

**Contact No.**

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final report within six months of completion of research. This can be submitted to the provincial Research Co-ordinator ([Health.Research@westerncape.gov.za](mailto:Health.Research@westerncape.gov.za)).
3. The reference number above should be quoted in all future correspondence.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Naledi', written over a dark redacted area.

**DR NT Naledi**

**DIRECTOR: HEALTH IMPACT ASSESSMENT**


**DATE: 22 /10/2013**

**CC**

**CEO: HOSPITAL**

## Appendix D Participant Information Sheet

(Afrikaans version included)

 The logo of the University of Cape Town, featuring a shield with a book and a scale, surrounded by the university's name in three languages: Afrikaans, English, and Xhosa.	<p><b>Department of Health and Rehabilitation Sciences</b></p> <p><b>Faculty of Health Sciences</b></p> <p>Divisions of Communications Sciences and Disorders, Nursing and Midwifery, Occupational Therapy, Physiotherapy</p> <p>F45 Old Main Building, Groote Schuur Hospital, Observatory 7925. Tel: +27 (0) 21 406 6401 Fax: +27 (0) 21 406 6323</p>
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### INFORMED CONSENT: INFORMATION SHEET

Dear Participant

My name is Fadia Gamielien and I am student at the University of Cape Town. I am conducting research as part of the Masters in Occupational Therapy degree.

The title of the research is: “*Community integration of male mental health care service users after their participation in a residential-based rehabilitation programme*”.

It is hoped that this study will help people understand what community integration means for men with a mental disorder who live in Heideveld, Cape Town. You have been approached to participate in this study because you have been in the Gateway\* rehabilitation programme.

You will be required to attend three interviews of approximately 45 minutes each. You will be asked to think of the benefits or other wise of this service for your community integration. You will also be asked to draw a map of key places in your area.

All the information collected will be treated as confidential. Only my supervisors and I will have access to any personal information. Your identity will remain confidential and pseudonyms (nicknames) will be used in the reports arising from the research.

You will be required to give your written consent and permission that the information provided by you can be used for the research purpose. All interviews will be audio recorded and the resource maps will be photographed for the purposes of data capture. Your participation is entirely voluntary and there is no penalty for not answering questions or stopping the interview at any time. You do not have to participate and if you say no, this will not affect you negatively in any way nor will it influence your access to health care.

You will not receive compensation for participating in the study although you might find that you derive some benefit from telling your story to another person. If you feel distressed during the interview process we can stop and talk about it. There are also people from the CHC who are willing to assist with things that might upset you. If you need to speak to anyone after I have left, the mental health nurse can be reached for an appointment at the number provided for your particular clinic.

Please contact me directly with any research related questions. I am available on (021) 406 6404.


This research will be supervised by Associate Professor Madeleine Duncan (021 406 6325) and Associate Professor Roshan Galvaan (021 406 6042). You are welcome to contact either of them if you have additional queries.

If you have any complaint or query about any aspect of this study, you may contact Professor Marc Blockman from the University of Cape Town Human Research Ethics Committee (HREC) 021 406 6338.

This research has been approved by the Research Ethics Committee and its reference number is HREC582/2013.

Please indicate that you understand what is required of you and that you are willing to participate by signing the consent form on the following page.

### Deelnemer Toestemming Vorm

	<p>Department of Health and Rehabilitation Sciences</p> <p>Faculty of Health Sciences</p> <p>Divisions of Communications Sciences and Disorders, Nursing and Midwifery, Occupational Therapy, Physiotherapy</p> <p>F45 Old Main Building, Groote Schuur Hospital, Observatory 7925. Tel: +27 (0) 21 406 6401 Fax: +27 (0) 21 406 6323</p>
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### INGELIGTE TOESTEMMING : INLIGTINGSBLAD

Geagte deelnemer

My naam is Fadia Gamielien en ek is 'n student aan die Universiteit van Kaapstad. Ek doen navorsing as deel van my Meesters in Arbeidsterapiegraad.

Die titel van die navorsing is: *“Gemeenskap integrasie van manlike geestelike gesondheid sorgdiens gebruikers, na hul deelname aan 'n residensiële rehabilitasie program”.*

Daar word gehoop dat hierdie studie sal mense help om te verstaan wat gemeenskap integrasie vir mense met 'n geestelike versteuring wat in Heideveld, Kaapstad woon, beteken. U is genader om deel te neem aan hierdie studie omdat jy by die Gateway\* rehabilitasieprogram betrokke was.

Jy sal verwag word om drie onderhoude van ongeveer 45 minute elk by te woon. Jy sal gevra word om oor die voordele of ander wyse van hierdie diens vir jou gemeenskap integrasie, te dink. Jy sal ook gevra word om 'n kaart van die belangrikste plekke in jou area te trek.

Al die inligting wat ingesamel word, sal as vertroulik hanteer word. Net my toesighouers en ek sal toegang hê tot enige persoonlike inligting. Jou identiteit sal vertroulik bly en skuilname (byname) sal gebruik word in die verslae wat voortspruit uit die navorsing.

Jy sal verwag word om jou skriftelike toestemming te gee dat die inligting wat deur u gegee word, vir navorsing doeleindigs gebruik kan word. Alle onderhoude sal klank aangeteken word en die hulpbron kaarte sal afgeneem word vir data opname doeleindes. U deelname is vrywillig en daar is geen straf as jy nie 'n vraag beantwoord nie of die onderhoud op enige tyd stop nie. Jy hoef nie deel te neem nie as jy nee sê nie. Dit sal jou nie negatief beïnvloed nie op enige manier nie. Dit sal ook nie jou toegang tot gesondheidsorg beïnvloed nie.

Jy sal nie vergoeding vir deelname aan die studie nie vervang nie, hoewel jy dalk vind dat jy voordeel uittrek van die storie wat jy aan 'n ander persoon vertel. As jy ongemaklik tydens die onderhoud proses voel, kan ons ophou en daaroor praat. Daar is ook mense uit die CHC wat bereid is om met die dinge wat jou dalk ontstel, te help. As jy met iemand wil praat nadat ek weg is, kan die geestelike gesondheid verpleegster bereik en 'n afspraak kan by die kliniek gemaak word.

Kontak my asseblief direk met enige navorsing verwante vrae. Ek is beskikbaar op (021) 406 6404.

Hierdie navorsing sal begelei word deur Mede-Professor Madeleine Duncan (021 406 6325) en Mede-Professor Roshan Galvaan (021 406 6042). Jy is welkom om een van hulle te kontak indien u verdere navrae het.


Indien u enige klagte of navrae het oor enige aspek van hierdie studie, kan jy met Professor Marc Blokman van die Universiteit van Kaapstad, Human Navorsingsetiëkkomitee (HREC) in verbinding tree op 021 406 6338

Hierdie navorsing is goedgekeur deur die Etekkomitee en sy verwysingsnommer is HREC582/2013

Dui asseblief aan dat jy verstaan wat van jou verwag word en dat jy bereid is om deel te neem, deur die ondertekening van die toestemming vorm op die volgende bladsy te voltooi.

## Appendix E Participant Signed Consent Form

(Afrikaans version included)

 The logo of the University of Cape Town, featuring a shield with a book and a scale, surrounded by the university's name in Afrikaans, English, and Xhosa: 'iYunivesithi yaseKapa · Universiteit van Kaapstad · University of Cape Town'.	<p><b>Department of Health and Rehabilitation Sciences</b></p> <p><b>Faculty of Health Sciences</b></p> <p>Divisions of Communications Sciences and Disorders, Nursing and Midwifery, Occupational Therapy, Physiotherapy</p> <p>F45 Old Main Building, Groote Schuur Hospital, Observatory 7925. Tel: +27 (0) 21 406 6401 Fax: +27 (0) 21 406 6323</p>
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### **INFORMED CONSENT FORM: Declaration by interviewee**

I hereby agree to participate in the research: “Community integration of male mental health care service users after their participation in a residential-based rehabilitation programme”.

The purpose of the study has been explained to me and I have had all my questions answered. I understand what is expected of me and know that this is a research project whose purpose is not to be of personal benefit to me. I do not feel that I am forced to take part in this interview and I am doing so of my own free will. I have been informed that refusal to participate will not influence my access to health care and that my confidentiality will be maintained at all times.

I have received the telephone numbers of people to contact should I need to speak to someone about issues, which may arise from my participation.

In addition to the above I hereby agree to the audio recording of these interviews as well as the photographing of the resource maps for the purpose of data capture. I understand that no personal identifying information will be released in any form. I understand that these recordings will be kept in a

secure, locked environment and will be destroyed six months after data capture and analysis is complete.

Signed:

\_\_\_\_\_  
Participant

-----  
Date and place

**Declaration by interviewer**


I, Fadia Gamiieldien (GMLFADOO1), declare that:

- I explained the information on the research to the participant.
- I encouraged them to ask questions and took adequate time to answer them.
- I am satisfied that they adequately understand all aspects of the research as discussed above
- I did not use a translator

Signed at (*place*) ..... on (*date*)  
..... 2014.

**Signature of researcher**.....

## Bylae Deelnemer Toestemming Vorm

	<p><b>Department of Health and Rehabilitation Sciences</b></p> <p><b>Faculty of Health Sciences</b></p> <p>Divisions of Communications Sciences and Disorders, Nursing and Midwifery, Occupational Therapy, Physiotherapy</p> <p>F45 Old Main Building, Groote Schuur Hospital, Observatory 7925. Tel: +27 (0) 21 406 6401 Fax: +27 (0) 21 406 6323</p>
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### **Ingeligte toestemmingsvorm : Verklaring deur die onderhoud gevoer**

Ek stem hiermee in om deel aan die navorsing te neem: *“Gemeenskap integrasie van manlike geestelike gesondheid sorg diens gebruikers na hul deelname aan 'n residensiële rehabilitasie program”*.

Die doel van die studie is aan my verduidelik en ek het al my vrae beantwoord. Ek verstaan wat van my verwag word en weet dat dit 'n navorsingsprojek wie se doel is nie om my persoonlik te bevoordeel nie. Ek voel nie dat ek gedwing was om deel te neem aan hierdie onderhoud nie en doen dit uit my eie vrye wil. Ek is ingelig dat weiering om deel te neem, nie my toegang tot gesondheidsorg sal beïnvloed nie, en dat my vertroulikheid gehandhaaf sal word ten alle tye.

Ek het die telefoon nommers van mense ontvante indien ek met hulle kontak wil maak sou ek met iemand wou praat oor kwessies wat mag ontstaan as gevolg van my deelname.

In bykomende tot die bogenoemde, stem ek hiermee in oor die klank-opname van hierdie onderhoud asook die afneem van die hulpbron kaarte vir die doel van data opname. Ek verstaan dat geen persoonlike inligting sal bekend gemaak word in enige vorm nie. Ek verstaan dat hierdie opnames sal in 'n veilige, toegesluit omgewing gehou word en sal ses maande nadat die ontleding en data opname voltooi is, vernietig word

Geteken:

\_\_\_\_\_

Deelnemer

-----

Datum en Plek

**Verklaring deur onderhoudvoerder**

Ek, Fadia Gamielien (GMLFADOO1), verklaar dat

- Ek die inligting oor die navorsing aan die deelnemer verduidelik.
- Ek hulle aangemoedig het om vrae te vra en voldoende tyd aan hulle toegegee om dit te beantwoord.
- Ek is tevrede dat hulle alle aspekte van die navorsing soos hierbo bespreek is, behoorlik verstaan.
- Ek het nie 'n vertaler gebruik nie.

Geteken by (*plek*) ..... op (*datum*)  
..... 2014.

**Handtekening van navorse :** .....

## **Appendix F Preliminary Interview Schedule**

(Afrikaans version included)

### **Interview Questions**

**We are going to talk about community integration after discharge from Gateway\*.**

Please tell me what you think community integration (CI) is?

**Prompt:** What do you understand by the words CI?

Some people think CI refers to the ability of a person to live, work, and enjoy his or her free time within the community setting

**Prompt:** What do you think of this description?

### **Community Map**

I am interested in how you spend your time and what your interests are. I would like you to draw a map of your community. This will help me understand the things you do every day, the places you go to and the people you meet.

**Prompt:** Please tell me about your map

**Prompt:** What are the particular resources or people that stand out for you?

**Prompt:** Where are these people and resources based?

**Prompt:** How do you use these resources?

**Having explored CI and your map, have you been in situations where you have felt that you are not part of your community?**

Can you describe these times to me?

**Let's now talk about your admission to the step down programme at Gateway.**

Please tell me about the programme that you followed at Gateway\*?

**Prompt:** What did you learn that was most helpful after discharge?

What did you find least helpful?

Is there anything else about the programme that you would like to tell me?

Thank you for sharing the story of your rehabilitation stay at Gateway\*.

### **Onderhoudskedule**

#### **Voorgestelde Vrae**

**Ons gaan oor die gemeenskaplike integrasie (GI) wat plaasvind nadat iemand ontslaan word van Gateway\*, gesels.**

Sê vir my wat dink jy is gemeenskap integrasie?

**Aanspoor:** Wat verstaan jy van die woorde GI?

Sommige mense dink GI verwys na die vermoë van 'n persoon om te lewe, werk, en om sy vrye tyd in die gemeenskap instelling te geniet.

**Aanspoor:** Wat dink jy van hierdie definisie / beskrywing?

#### **Gemeenskap Legkaart**

Ek is geïnteresseerd in hoe jy jou tyd spandeer en wat jou belangstellings is. Kan jy vir my n legkaart teken. Dit sal my help om jou daaglikse aktiwiteite, die plekke waarnatoe jy gaan, die mense wat jy ontmoet en die dinge wat jy doen te verstaan.

**Aanspoor:** Vertel my van jou kaart

**Aanspoor:** Wat is die spesifieke hulpbronne of mense wat vir jou uitstaan?

**Aanspoor:** Waar is hierdie mense en hulpbronne gebaseer?

**Aanspoor:** Hoe gebruik jy hierdie hulpbronne?

**Nadat ons GI en jou kaat verken het, was jy al in situasies waar jy voel dat jy nie deel was van die gemeenskap is nie?**

Kan jy hierdie tye vir my verduidelik?

**Kom ons praat oor jou toelating tot die stap-af program by Gateway\*.**

Vertel my asseblief oor die program wat jy by Gateway\* gevolg het?

**Aanspoor:** Wat het jy geleer wat die meeste nuttig was nadat jy ontslaan was?

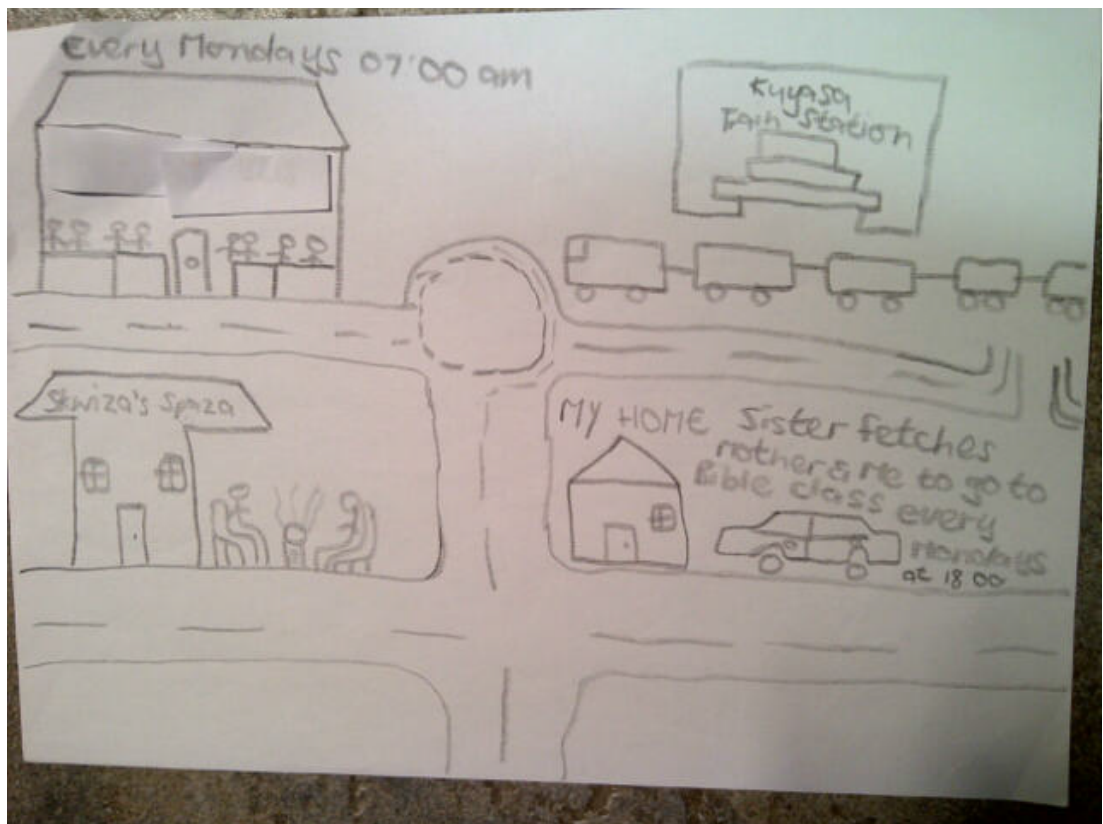
Wat het jy minstens nuttig gevind?

Is daar enigiets anders oor die program wat jy vir my wil vertel?

Dankie dat jy jou storie van jou rehabilitasie verblyf by Gateway\* gedeel het.

**Het jy enige vrae wat jy aan my wil rig?**

## Appendix G Resource Map Sample



## **Appendix H Document list**

A written document analysis worksheet was completed for each of the following documents:

- Gateway Step down/step up facility report (2008)
- Gateway Description of service (2008)
- Gateway Step down/step up facilities in the Western Cape Metro operational plan (2008)
- Standard operating procedures for step down/step up facilities (2010)
- Policy framework on intermediate care (2012)
- Gateway information pamphlet (2011)
- Gateway programme time table (2011)
- Gateway programme hand outs and CV form outline (2011)

## Appendix I Data analysis spiral table

(Creswell, 2007, p.183)

<b>Data management</b>	Data files created and organized. Manual copy as well as electronic copy created using NVivo
<b>Reading and memoing</b>	I immersed myself in the data by reading each transcript several times while making notes along the margin. This was used to highlight key points that arose from the data and which resulted in the identification of codes
<b>Describing</b>	A detailed description of each participant was written up and it included demographics, presentation, health history and participation in the interviews
<b>Classifying</b>	Codes were grouped into subcategories and overlapping subcategories were grouped under categories. Lean coding from these broad categories was used to review and re-review the database. I remained open to additional categories and I worked with emerging data until saturation became evident (i.e. the same codes started surfacing repeatedly). The data was 'winnowed' (Creswell, 2012,p.184) as not all information could be used in the study. The categories were combined into an overarching theme, which was used to write up the narrative so as to provide a detailed description of the case.
<b>Interpreting</b>	Data was interpreted in a cyclical manner, as it was an iterative process whereby I engaged in cross case analysis looking for knowledge, which can contribute to the research literature.
<b>Representing and visualizing</b>	The findings are presented in chapter's 4 and 5 through the use of case descriptions, verbatim quotes and tables. Member-checking was used to validate the findings.

## Appendix J Audit trail

Process notes as per (Lincoln & Guba, 1985) six elements of an audit trail

Audit Trail Element	Examples	My Activities
Raw data	Audio data, Interview transcripts, document analysis, photographs, field note, reflexive journal notes	Early immersion in data  Suspension of own assumptions  Triangulation of data generation methods
Data reduction and analysis	Condensed notes and summaries, ideas on emerging concepts, transcript notes	Data triangulation through corroboration of findings and preventions of assumptions surfacing
Data reconstruction and synthesis	Organisation of themes, categories and sub-categories  Documenting findings based on interpretation and inferences.  Writing discussion and recommendations with connections to existing literature	Ensuring participants' voice comes through in the findings  Interaction with peers and supervisors  Follow-up member-checking interviews
Process notes	Methodology chapter (procedure, research design and rigour) and audit trail to ensure trustworthiness and authenticity	Use of NVivo to organise different elements of the research

Materials related to intention	Research proposal, ethics approval, consent forms, reflexivity journal	Documents in appendices
Instrument development	Pilot work, interview questionnaire, draft reports and feedback notes	Interview questions revised after pilot interview

## **Appendix K Interpretation of raw data**

NVivo was used to store and organise all elements related to the research

### Transcribed Interview:

*“Well look the thing is here I sort of push the envelope. Brenda (see footnote 48) is very nice and she lets me figure out my own way, ja, a very, very nice lady and so I mean I don’t have to get up at six. I mean sometimes I get up at nine. Sometimes we even take a chance and I sleep whole day, uhm, but it’s not supposed to be like that”*

### Field Notes (to support transcription)

Relaxed atmosphere in house, we walked through the kitchen where Brenda was cleaning up. 15 minutes later, Brenda came to knock to say she was leaving to do weekend shopping and did we need anything. Our interview was also scheduled at 10am, which is usually a time in which residents are not meant to be in the house.

### Code

Code: Flexibility in household

Subcategory: Find own routine within structure

Category: There is no one size for all

### Findings excerpt

Flexibility to develop his own routine is appreciated by Mikaeel as an offering by the group home.

### Discussion excerpt

A focus on the benefits of occupation means considering feelings of social cohesion, meaning, purpose, normalisation, routine, competence, productivity, skill acquisition and pleasure within the planned intervention.

This requires flexibility and creativity with due consideration to the roles of position, space and place in occupational engagement.

## Appendix L List of footnotes

1. Apartheid is the Afrikaans word for “separateness”. It was the racial, social policy introduced by the National Party government of South Africa in 1948 and it was upheld until 1994 (Little, 2015). The late Nelson Mandela (1993) had this to say about apartheid in his Nobel lecture: “We speak here of the challenge of the dichotomies of war and peace, violence and non-violence, racism and human dignity, oppression and repression and liberty and human rights, poverty and freedom from want.”
2. Pseudonym used for the step down/step up facility referred to in this study. Step down refers to referral from a psychiatric hospital to Gateway and step up refers to referral from a community health centre to Gateway.
3. Coloured refers to South Africans who have creolised identities, which are shaped and re-shaped by current and historical experiences that bind them together. These include slavery and oppressive treatment during apartheid (Erasmus, 2000, p.84).
4. Cape Flats refers to an expansive low lying flat area outside of the Cape Town city centre to which ‘non-whites’ were forcibly moved during apartheid. Within the Cape Flats there are further racial, economic and spatial divisions between coloured communities and African townships (Standing, 2003).
5. The PHC approach as defined according to the Alma Ata Declaration of 1978 (World Health Organization, 2008).
6. The Gini co-efficient for South Africa is currently 0.70 (Barrientos et al., 2013). This ratio is used to measure inequality in a country based on income distribution. The higher the number the greater the inequality. South Africa has the worlds’ highest Gini coefficient. There is currently debate around whether South Africa should have two

calculations; one based on income from work and one which considers income inclusive of social grants (Rossouw, Claassens, Plessis, & Bosch, 2010). 35% of the population live on ZAR116 per day.

7. See Appendix A for the literature search scope.
8. Health systems refer to the different people, institutions and resources that deliver services in order to meet the needs of the target population. Health systems contribute to the social determinants of health and are needed to improve health status and address health inequalities (Ataguba et al., 2011).
9. Refers to the continuous cycle of admission, discharge and readmission that MHSUs find themselves in.
10. The concept of 'family' is a Westernised notion of the nuclear social unit. In the African context, people are more likely to be assimilated into a 'household' consisting of parents, grandparents, aunts, uncles, cousins and distant relatives (Banda, 2014). Due to the death of parents as a result of HIV/AIDS, a significant proportion of the population under the age of 18 are not living in 'families' but reside in government and NPO care facilities (Blas & Kurup, 2010).
11. Our goals or 'ends' are guided creatively and imaginatively 'in view' of our future possibilities (Cutchin et al., 2008).
12. See footnote 3 for explanation of Cape Flats.
13. See footnote 2.
14. Pseudonym used for the referring specialist psychiatric hospital in this study.
15. Residential suburbs with formal and informal housing designated for black people in the apartheid era.
16. More men are referred to the programme than women. The prevalence of serious mental disorders are higher in men whereas

more women are diagnosed with depression and anxiety disorders (Hamad, Fernald, Karlan, & Zinman, 2008). At the time that the study was concluded Gateway was an all-male facility.

17. Gatekeepers are individuals in authority positions whose approval and support is central for access to participants and entry into the research context (Kelly, 2006b).
18. I conducted a brief mental state examination during the initial invitation conversation. I asked questions related to orientation to time, place and person in order to assess this.
19. Pseudonym of participants own choosing is used to ensure confidentiality.
20. The year of admission and not the dates of admission and discharge are used to ensure confidentiality.
21. See 3.10.1.
22. The pseudonym was used to ensure anonymity of the group home. The name was selected as a reflection of the benefit that Mikael derives from living there. It is affiliated to an organisation, which provides accommodation as well as a daily clubhouse service for socialisation, support and craft opportunities.
23. *“Clinical pathway and referral pathway: Family and individual clients appointments. Individualised treatment plans are formalised with the patient.”* (Associated Psychiatric Hospitals, 2010; Occupational Therapy Department, 2011a, 2011b).
24. The informal economy which includes fraudulent activities contributes between 4-6% of the GDP of South Africa (Ligthelm, 2006).
25. A South African study on illicit drug use amongst urban dwellers conducted by Peltzer, Simbayi, Kalichman, Jooste and Cloete (2009) found that drug use amongst participants were as follows: 25% for cannabis, 7.3% for methamphetamine (tik) , 5.4% for mandrax, 3.3%

for pills from the street and 1.2% for any drug injected by needle. Additionally they found that over a 12-month period nearly one in three urban dwellers showed symptoms of drug addiction.

26. Worldwide, tik use is the highest in Cape Town with 90% of users being coloured (Plueddemann in Kapp, 2008). According to the South African Community Epidemiology Network on Drug Use (SACENDU) the drug was originally introduced to Cape Flats communities as part of gang culture (Kapp, 2008) although its use has now spread more widely. The South African Medical Research Council (MRC) reports tik as being the primary or secondary source of abuse for which people seek treatment (Kapp, 2008). In this regard it is ahead of alcohol abuse. An increase in drug use in the Western Cape has a number of consequences which include the following: influence on sexual risk taking which increases risk of HIV infection, increase in heroin addiction accompanying use of tik, long term psychological effects of tik has seen an increase in psychiatric admissions amongst users, low- birth-weight of babies born to women who abuse tik and an increase in tik-related crimes (Kapp, 2008; Peltzer et al., 2009).
27. Bolo's thinking was illogical and tangential. His memory was poor and he had psychomotor retardation.
28. Extract from Reflective notes: 12/02/14 Met Gershwin at OPD today to explain my study. He was there to see the doctor and wanted to meet me first. He was wearing a T-shirt with "I'm socially responsive on it". What an interesting person. He agreed to participate saying he has lots to say!
29. Reflective notes 18/02/14: I called Gershwin on Monday to remind him about today. When I got to the library he had been waiting for a while (according to the librarian he came an hour before our scheduled appointment time). He said he's hungry and wants to eat first, but wants to choose his own eats! He really pushes the boundaries and I feel as if he is testing me. I agreed to go to the shop with him, and I could sense his surprise that I would walk in the area with him. I think I

passed that test! It is not unlike where I live but my willingness seemed to set the scene for cooperation.

30. He was watching television (TV) and had the delusion that it was the end of the world. His auditory hallucination led him to believe that the TV was telling him what to do. He acted on his delusion and hallucination by swallowing barbed wire and floor polish and when he told his parents they prayed for him and called the Reverend who took him to hospital. He had to have surgery to repair the damage caused by the wire.
31. Research journal note 12/02/14 "...also he goes off on a tangent quite a lot so I had to bring him back while still being mindful of the need to give him time to talk and let things evolve."
32. A low socioeconomic residential suburb with formal and informal housing designated for black people in the apartheid era.
33. While part of this confusion is related to Emmanuel's thinking it is also an indication of how complex community integration is for persons with chronic mental illness.
34. The pseudonym, Community Care Place was used because it is reflective of the organisation's aim of supporting people with psychiatric disabilities in community living.
35. The pseudonym Safe House was used based on a quote from Dan that living there made him feel safe.
36. Dan collects his TB medication at one clinic, which he attends, on alternate weekdays as part of the TB adherence programme. In addition to this he attends a monthly clinic in another suburb where he collects his psychotropic medication for his psychiatric disorder. There is currently no integrated clinic that is able to offer him both these services.
37. Pseudonym used.

38. Pseudonym used.
39. Pseudonym used.
40. In the mental health service platform, Gateway is a level of care between the specialist psychiatric hospital and the 'naked' community (integrated primary health service).
41. MHSUs can be admitted to a psychiatric hospital on an involuntary basis according to the MHCA if they are assessed as posing a danger to themselves or others (South African Government, 2002). Gateway only accepts voluntary patients without behavioural problems or unstable medical conditions.
42. Professional judgement about fitness for work of persons with psychiatric disability is limited to an assessment of the alleviation of positive symptoms allowing the MHSU to participate in the Gateway programme. It does not consider the individual work skills and access to employment resources of MHSUs in the programme. This has implications for community integration as work opportunities are not explored or protected while MHSUs are at Gateway.
43. Pseudonym used. Refers to fellow resident in Gateway programme.
44. A urine test is taken after MHSUs return from weekend leave to ascertain whether or not they used illicit drugs. A positive result could lead to MHSUs losing their place in the programme. There is a high incidence of dual diagnosis where MHSUs have a substance use disorder along with their mental disorder.
45. Pseudonym used.
46. MHSUs are challenged by high rates of unemployment, violence and crime, medication non-compliance, poor social circumstances, poverty and mental disorders with co-occurring rates of substance abuse.
47. Informal shop in township area.
48. Pseudonym used.

49. A tik-induced state of preoccupation used in Cape Town street youth culture to describe feeling both mentally absorbed while simultaneously being withdrawn and absent-minded.