

**THE INFLUENCES THAT IMPACT ON THE WORK-LIVES OF
PEOPLE WITH PSYCHIATRIC DISABILITY: AN
INTERPRETIVE BIOGRAPHY**

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by

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TO MY PARENTS

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Abstract

Rationale: The new South African Constitution speaks strongly against discrimination of any kind. Research evidence and experience have shown that people with psychiatric disability are discriminated against when they attempt to enter the world of work. Numerous barriers, most importantly attitudinal barriers, hinder the acquisition of work, as well as people with psychiatric disability's ability to successfully maintain their work. Developments in South African labour legislation have pathed the way for the achievement of equity and for the development of affirmative action strategies that will promote the participation of disabled people in work. Discrimination of any kind against people with psychiatric disability is unacceptable and should no longer be tolerated.

Aim: This study explored the influences that helped or hindered the participation of people with psychiatric disability in the world of work.

Method: Interpretive biography was utilised to explore the experiences of people with psychiatric disability in the Western Cape, South Africa. Using maximum variation sampling, 17 participants with an Axis I DSMIV-R diagnosis who had been working or attempted to find work, were identified. Life story narratives were elicited during an average of 3 individual interviews with each participant. Processes of analysis and interpretation were informed by a combination of paradigmatic narrative analysis and narrative analysis strategies.

Findings: The findings revealed a complex interplay of influences that shaped the identity of participants in ways that would assist or hinder their participation in work. These influences originated with psychiatric impairment and influenced the construction of identity in line with participants' perceived acceptability in social contexts that included work. Strategies employed by participants to live with difference were understood and the impact on decisions about work considered. Participation in work, an essential ingredient in the promotion of occupational justice, was shown to have an important role

in identity construction, in the process of recovery and as a mechanism for achieving wellness. The Model of Participation and Restriction was developed to show the main influences that impact on people with psychiatric disability's tendency to participate or restrict their involvement in chosen occupations.

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LIST OF ABBREVIATIONS

CCMA	Centre for Conflict, Mediation and Arbitration
CGP	Code of Good Practice (2001)
CHW	Community health worker
DPO	Disabled people's organisation
DPSA	Disabled People South Africa
DSM IV	Diagnostic and Statistical Manual of Mental Disorder (1994)
EEA	Employment Equity Act (1998)
GAF	Global Assessment of Functioning
HEQC	Higher Education Quality Committee
HPCSA	Health Professions Council of South Africa
INDS	Integrated National Disability Strategy White Paper (1997)
IPS	Individual Placement and Support (programme)
NGO	Non governmental organisation
NQF	National Qualifications Framework
OCD	Obsessive compulsive disorder
OLM	Open labour market
RCT	Randomised control trial
PANSS	Positive and Negative Syndrome Scale
SETA	Sector Education And Training Authority
SGB	Standards Generating Body
TEP	Transitional Employment Programme

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NOTES ON THE USE OF TERMINOLOGY

Terminology used in the field of psychiatry has always been problematic. Each term is based on a set of complex arguments that situate the user of the terminology within a particular point of view. In South Africa, most people would use terminology such as *mental patient/client* and *psychiatric patient/client* interchangeably. South African health professionals are trained according to the Diagnostic and Statistical Manual of Mental Disorder (1994) (DSM IV) classification and would therefore be comfortable with use of the term *mental disorder* whereas, *mental illness* is very often used in publications or in general discussion. An idiosyncrasy of health professionals is to use the name of a (psychiatric) hospital, to refer to a present or past patient of the hospital, for example *(ex) Valkenberg patient* or *(ex) Stikland patient*.

A relatively new trend is to use terms such as *service user*, *consumer* or *survivor*. These terms are well understood in health and lay contexts in South Africa but mostly used by those outside traditional government psychiatry settings. Service organisations that fall within the Non Governmental Organisation (NGO) sector seem to be more aware of the problems associated with the use of traditional terminology.

Disabled People South Africa (DPSA), a prominent Disabled People's Organisation (DPO), proposed the use of *disabled people* as the generic term to use. The main reason for this choice is its alignment with the social model of disability. This model rejects the notion that impairments are the cause of limitations experienced; instead, barriers that originate from the environment limit participation. The social model does however accept *impairment* as a legitimate term that is used to capture a particular illness, injury or condition. It is important to note that DPSA's membership predominantly consists of disabled people with physical or sensory impairments. The terms

psychiatrically disabled people and *people with psychiatric disability* are both acceptable as terms that mirror the positions of DPSA membership. Another reason why the use of *psychiatric disability* is becoming increasingly popular is the implied affiliation to the disability movement and to affirmative action programmes developed to promote the concerns of disabled people. This term fits with new employment legislation and with developments that position disability as a human rights issue.

My decision to use *people with psychiatric disability* and *people with psychiatric impairment* is in line with the spirit of the Social Model of Disability. *Psychiatric disability* would therefore take cognisance of the barriers, (mostly attitudinal), that originate from a disabling environment and that prevent equal participation. *Psychiatric impairment* is used to describe the direct impact of a condition that falls within the diagnostic categories of the DSM IV on the person (where barriers from the environment have not had an impact). Diagnostic terms, such as *depression* or *schizophrenia* were used consciously in this study, despite some role players in the disability field not supporting their use.

The generic disadvantage of all terminology is that people are labelled in one way or another and that the label is then used to refer to the person (as if the entire person can somehow be represented by the label). Traditional medical model labels emphasise limitations, (that are almost always considered to be a weakness), thereby foregrounding a deficit, despite a full range of characteristics that would better represent the person.

The terminology used by other authors was however mirrored without change. Such terms were:

- *People with psychiatric disability*
- *People with (severe) mental illness*
- *People with mental disorders*
- *People/persons with mental ill-health*

- *Consumers (of mental health services)*
- *(Mental health) service users*
- *Clients*
- *Patients*
- *Survivors (of mental illness)*

I used the term *participant* to refer to those people with psychiatric disability, who constitute the sample and who therefore participated in the process of knowledge construction. This term is used to depict their contribution to the understandings gleaned and presented in this study. Again, terminology used by other researchers was mirrored:

- *Subjects*
- *Participants*
- *Interviewees*
- *Respondents*

During interviews I attempted to mirror the terminology, used spontaneously by participants themselves. An attempt was made to identify such terms during introductory conversations; the same terminology was then used during the interview. Participants were not equally comfortable in acknowledging the presence of a psychiatric impairment by referring directly to it. It struck me that the less comfortable they felt, the more 'removed' terminology would be. For example, the obvious ease with which some participants referred to "my depression" or would talk about "being very Bipolar today" stood in contrast to participants who avoided direct references and would talk about "when it happened" or "when I had to go to hospital". Verbalising the experiencing of a relapse was similarly varied. One participant spoke about "having a breakthrough" while, at the other end of the scale a participant could only bring himself to refer to relapse in evasive, indirect and vague terms such as "when *that* happened to me – and I had to be hospitalised" or "I cannot allow *that* to happen to me again". Other terms

used to denote periods during which they actively experienced symptoms were "(nervous) breakdown" or "getting sick".

By the time consent forms had to be signed, the term *psychiatric disability* was introduced -because it appeared on the consent form. Each participant was asked how they felt about this term. This often led to a discussion about the way participants thought they were perceived by society in general. My rationale for using *psychiatric disability* was explained by highlighting the purpose of the study as situated within the context of equity in participation for people with disability. I explained that no one term was more acceptable than another and that personal preference was understood and accepted.

Delineating the scope of concern

It is necessary to clarify the particular focus in the present study. In order to do this a differentiation has to be made between people with broad *mental health concerns* and people with particular impairments that are traditionally grouped under the term *mental illness*. Such categories are *intellectual impairment* and *psychiatric impairment* (also called *emotional impairment*). The broader category, *people with mental health concerns* would include generalised emotional difficulties, of the type that most people encounter in varying degrees and at different stages in their lives.

The DSM IV classification system was chosen mainly because of the differentiation it makes between Axis I and Axis II diagnostic categories. This research included only people with Axis I psychiatric impairments. The terms *people with mental disability/impairment* was used at those times when broader reference is made to include all categories of impairment (or both Axis I and Axis II categories). When even broader reference is made to also include people who fall outside particular diagnoses, but who are experiencing emotional difficulties, then *mental health* and *mental ill-health* are used. A

differentiation has to be made between broad *mental health* concerns, of the type that most people encounter in varying degrees at different stages, and psychiatric impairment. The differences between these two concepts are often blurred, with the result that the domain is further complicated. By broad *mental health concerns* I mean, for example, exposure to unhealthy stress, feelings of depression during times of family crises or dysthymia associated with long-term dissatisfaction with a work situation that cannot be improved.

Work, employment and occupation

These terms are defined in the Appendix 1. The terms *work* and *employment* were used to convey understandings that are the same as is generally used in society. However, *occupation* is used to convey a particular meaning that is different from the way it would generally be used; here it means "chunks or units of culturally and personally meaningful activity within the stream of human behaviour {Yerxa, 1990 #65}.

A differentiation between *work* and *employment* is required, together with a rationale for focussing on work. For the purpose of this study work is defined as 'a goal-directed activity that produces something of acknowledged value'. The important elements of work-occupations would therefore be the experience of producing something and the recognition of value. 'Producing something' includes tangible and intangible products; examples of intangible products would be child care or knowledge production. Work contexts include the home, employment settings, school or university and community. This definition was developed to capture a broad range of work categories and contexts, including being self employed. Employment is 'the state of being commissioned to work for another in return for remuneration'.

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Chapter 1: INTRODUCTION

Introduction

The tendency to believe that somebody with a psychiatric impairment necessarily will have a reduced capacity to work is largely based on generalisations that are contradicted by many who continue to work. To alter one's view of a person's ability to work, solely because of a diagnosis and without verification of reduced work capacity, is discriminatory. Yet, an automatic tendency has been to anticipate incompetence or a reduced ability to maintain work in so far as people with psychiatric disability are concerned. Such practices have led to the exclusion of people with psychiatric impairment from work, turning their impairment into a disability. Exclusion impacts negatively on the health and wellness of people because of the many advantages of work itself; and the fact that it is often the only source through which a range of other needs are met.

In this first chapter a justification for the study will be provided, the emergence of the research is considered and an introductory overview of the pertinent issues will be given. The aim, purpose and rationale for the research will be introduced and information will be provided to delineate the scope of the research. Statistics are provided to show the size of the problem.

The central argument of this thesis is that complex processes interplay to influence the participation of people with psychiatric disability in the world of work. Factors that promote participation in work, or that impose restrictions on such participation, originate at the personal (micro) level, within group (meso) contexts (including relationship dynamics in the family and at work)

and through societal (macro) influences¹. It will be argued that people with psychiatric impairment become disabled primarily as a result of attitudinal barriers that make it difficult for them to find and maintain work. Attitudinal barriers operate at a personal level in parallel with experiences of alienation and in anticipation of stigma at meso and macro levels. In other words, disability stems from the inability of society to allow full integration and equal participation of people with psychiatric impairment, rather than from the impact of the impairment itself.

It will be illustrated through this thesis that the stigmatisation of psychiatric impairment, as a condition of society, is one of the main negative influences that interferes directly and indirectly with participation in work. However, the impact of stigma is not always immediately noticeable; it impinges on the identity construction of people with psychiatric disability in complex ways. It will be shown that powerful attitudinal barriers were the result of misinformation and that these culminated in stigma. Participation in work was hindered when stigma was being experienced and also when it was anticipated (by those who had not actually experienced stigmatisation and those that had). An explanation will be offered to show why the stigma anticipated by participants had at least as much negative consequence as actual experiences did. The consequence of stigma is exclusion or marginalisation of people with psychiatric disability. The dominance of attitudinal barriers (including stigma), and the relative absence of other barriers, such as physical barriers, that are often given precedence in drives to facilitate inclusion of disabled people, sets people with psychiatric disability apart and contributes to the alienation and disempowerment experienced by them.

¹ Bronfenbrenner differentiated three levels of environmental dimensions, which he called the macro (societal), meso (community) or micro (personal) dimensions Bronfenbrenner, U. (1979) Towards an Experimental Ecology of Human Development., *American Psychologist*, **22**, 513-31.

A full appreciation of the negative consequences that result when people with psychiatric disability are excluded from work can only be gained if the positive gains from participation in work are understood. The findings will show why participation in work is viewed as an essential ingredient for the achievement of wellness and for the management of identity. The injustice of exclusion from work is confounded by the fact that work has great potential to facilitate the integration of people with psychiatric disability into mainstream society.

1.1. The emergence of the research

The starting point for this study was my own experience of working in psychiatric settings as an occupational therapist. Over a number of years I came to realise that very little attention was given to the fact that people, who had received treatment for psychiatric impairments, were not working. In rehabilitation units, the focus of intervention remained locked into the alleviation of symptomatology. Some attention was given to improving relationships, mostly family relationships, and the teaching of 'self-help' skills. Rehabilitation programmes consisted of pharmacological intervention, life skills and social skills training, group therapy and (for some) psychotherapy. The operational assumption seemed to be that finding work was something that patients did, on their own, after discharge. This 'neglect' did not appear to be related to a lack of commitment on the part of health professionals; instead it was considered a limitation of the mental health system with its predominantly medical model interpretation of health needs. A further limitation has been the lack of contribution from sectors other than health, most notably the labour and education sectors. However, I believed attitudinal factors to underlie the above-mentioned limitations. It became clear that people with psychiatric impairment were not being assisted to find work, thereby contributing to their disability experience. In fact, the absence of work expectations, subtle messages that question their ability to work and

an absence of work rehabilitation might even interfere with the intention to work.

My expectation was that an in-depth exploration of the influences that facilitate or hinder work would generate fresh insights that could then be used to develop new interventions with which to effectively support people with psychiatric disability to work. The need for knowledge derived from people's actual experiences and from the South African context became increasingly pertinent when a literature search failed to produce anything of relevance. Without knowledge that is appropriate, specific and contextually relevant service providers are left in the dark, not knowing how to change practice to better serve the needs of people with psychiatric disabilities. Recent changes in legislation highlighted the lack of employment equity experienced by disabled people and identified it as an important human rights issue. A new appreciation of human rights problematised the tendency to believe that disabled people had a reduced need, capacity and/or resilience to participate in work. The exclusion experienced by people with psychiatric disability was therefore understood to be a complex issue with equal opportunity implications that, while neglected, was also a human rights concern.

1.2. Aim

The aim of this study was: To explore the influences that impact on the work-lives of people with psychiatric disability.

1.3. Purpose

The purpose of the study was to understand the influences that impacted on the work-lives of people with psychiatric disability so that the findings could assist with service development. New approaches should prioritise attainment

of work for people with psychiatric disability as a priority; something the current services have failed to accomplish. This failure would suggest that an entirely different approach was required. It was my belief that the direction and best strategies of such an approach could be developed, based on the experiences of people with psychiatric disability.

Research findings would also assist service providers to interpret and promote the implementation of labour legislation intended to equalise work opportunities for people with psychiatric disability. Findings could directly inform reasonable accommodation and the development of affirmative action programmes. Policies that currently do not give sufficient attention to the promotion of work as a strategy had to be challenged because achievement of equity for disabled people has become a major concern. Existing service providers, who are already assisting people with psychiatric disability in their attempts at integration into the world of work, require research direction derived within the South African context.

An interpretive biography design, with an interpretive stance and a post-modern orientation, was used in the present study. This was chosen in order to explore the influences that impacted on the participation of people with psychiatric disability in the world of work. The motivation for this particular direction was fuelled by a need to understand my observation that some people with psychiatric disability continued to work productively, whereas others were not able to do so. A satisfactory explanation of the factors that promoted, or that hindered, the participation of people with psychiatric impairment in work could not be found in the literature.

1.4. Justification for the study

Several pertinent factors made this study relevant at the present time in the context of health and social care in South Africa and include:

- ◆ A legislative framework that promotes employment equity.
- ◆ The need for quality information to guide practice developments.
- ◆ The adoption of the social model of disability.
- ◆ The intention to broaden the scope of services for people with psychiatric disability.
- ◆ An increasing realisation of the value of work in promoting health.

1.4.1. Mental health, mental illness and psychiatric disability

To clarify the particular focus in this study, a differentiation has to be made between *people with mental health concerns*, *people with mental illness*, *people with psychiatric impairment* and *people with psychiatric disability*.

Mental illness, a term that is regularly used to capture a range of impairments, includes *intellectual impairments*. These impairments, or diagnoses, are classified using the Diagnostic and Statistical Manual of Mental Disorder (1994) (DSMIV) or the International Classification of Function (ICF) that was developed by the World Health Organisation (2001). The term, *people with psychiatric impairment*, means the same as *people with mental illness*, with the exception that it excludes *people with intellectual impairment*. People with *mental health concerns* are those that do not necessarily have a diagnosed impairment that falls within the domain of psychiatry; these people would be experiencing emotional difficulties because of personal circumstances or possibly as a secondary condition of a physical impairment, for example, HIV/Aids or Parkinson's disease. The difference between psychiatric impairment and psychiatric disability is located in the concept 'disability'. The Social Model of Disability definition evolved from an original definition by the Union of the Physically Impaired Against Segregation (UPIAS) in 1976 in which disability is understood as having been imposed, on top of impairments, by a society that isolates and excludes people with impairments from full participation in society (Oliver, 2004).

The differentiation between *people with broad mental health concerns* and *people with psychiatric disability* is seldom made. One might argue that such a differentiation is unnecessary within a medical model context wherein pharmacological intervention would be the dominant solution in all cases. I argue here that differentiation is important when other models are applied, for example, health prevention and promotion or rehabilitation. When the aim of service intervention is to assist with (re)integration into work, clear differentiation is essential as this will guide the focus of intervention. It is important to note that this call for clear differentiation should not be understood to mean that broad mental health concerns are less legitimate. To limit the scope would be to exclude important concerns, for example, the distress experienced in situations of extreme poverty. It is my belief that the scope of mental health practitioners' concern should remain broad, but that more attention should be given into differentiating between different categories of need, in order to focus service provision.

The physical, cognitive and emotional consequences of psychiatric impairment episodically affect functioning in social and vocational realms, but discrimination compounds the impact in ways that are not usually recognised. Thomason suggested that The Americans with Disabilities Act "brought to the fore a recognition that disability has at least as much to do with the attitudes of employers and other workers and the design of workplaces as it does with the functional limitations of the injured workers" (Thomason, 1998:1). This statement was made with physical disability in mind, however, a strong argument can be made that people with psychiatric disability face employer attitudes that are even more negative (Marrone, Balzell and Gold, 1995; Link, Struening, Neese-Todd, Asmussen and Phelan, 2001). Anti-discrimination legislation is welcomed for the positive impact it could have in equalisation of opportunities for disabled people, in addition to considering workplace adjustments that 'enable' people with psychiatric disability.

My belief in the potential of work to promote the wellness of people with psychiatric disability was a key assumption and the main reason for undertaking this research. As Stanfeld argued:

“To be unemployed when you want to be working is indisputably bad for both mental and physical health” (Stanfeld, 2002:96).

1.4.2. Occupational justice and injustice

Occupational justice² might be understood to be prevailing when the unemployment rate amongst disabled people and non-disabled people is the same; this is not the case in South Africa.

It is recognised that disabled people have been excluded from institutions of mainstream society, including education and work, for a number of reasons. The Integrated National Disability Strategy White Paper (INDS) cited three reasons (Office of the Deputy President T. M. Mbeki, 1997):

- ◆ the political and economic inequalities of the apartheid system,
- ◆ social attitudes that continue to perpetuate stereotypes of disabled people as dependent and less competent
- ◆ a discriminatory and weak legislative framework which sanctioned and reinforced exclusionary barriers.

The last reason is, however, no longer relevant, since the promulgation of new labour legislation, specifically the Employment Equity Act of 1998 (EEA) (Department of Labour, 1998) and the accompanying Code of Good Practice (CGP) (Department of Labour, 2001). The Skills Development Levies Act of 1999 (Department of Labour, 1999) promises to bring significant advancement of work integration of disabled people through opportunities afforded for training and tax incentives made available to employers.

² Occupational justice occurs when economic, political and social forces create equitable opportunities and the means for people to choose, organise and perform occupations they find useful or meaningful in their environment (Townsend & Wilcock; 2004).

1.5. Research outcomes

The research undertaken confirmed many of the broad beliefs that led to the study, providing clarity and specificity in each instance. First, the strong influence of attitudinal barriers was expected at the outset but the scope of such barriers was not comprehended. For example, the mechanisms employed by people with psychiatric disability themselves that deliberately or unwittingly maintained attitudinal barriers were particularly noteworthy. Second, the complexity of factors that enabled and disabled participation in work was anticipated, but without specific knowledge of their nature or how such factors were experienced. For example, the negative consequences of stigma were anticipated, but without a clear picture of the sources and mechanisms through which this strong attitudinal barrier was operationalised in work contexts. Third, a void of research to show experiences of people with psychiatric disability particularly relevant to disabled people living within South Africa meant that beliefs and opinions were based on clinical experience and research produced in developed countries; such knowledge was therefore anecdotal and sketchy. Particular deficits in available research to guide practice, which is addressed in Chapter 3, further diminished the confidence with which research findings might be applied. For example, whilst stigma is accepted to be an international phenomenon it is understood that health beliefs, health practices, power dynamics and even health systems will shape the nature of the stigma, and the power with which such attitudes will impact on the actual experience of disabled people subjected to it. Fourth, a firm belief in the value of work was confirmed by the research process and findings. Empirical evidence for the value of work is something that is, for the most part, absent from occupational therapy literature. Other issues that emerged will be argued:

- ◆ There has been, and continues to be, a lack of appreciation of the importance of work for people with psychiatric disability.
- ◆ There has been a propensity to underestimate the ability of people with psychiatric impairment to work and to overestimate risk factors.

- ◆ Legislation, until 1998, impeded people with psychiatric disability from gaining and maintaining a work life. In the absence of anti-discrimination legislation, work was often disrupted by relapse rather than inability to cope with the demands of the work. The new legislative environment protects against discrimination on the basis of disability and calls for affirmative programmes to facilitate the participation of disabled people in work. Legislation alone has however not made much obvious difference to date.
- ◆ There has been over inclusive labelling of problems at work that have been ascribed to mental health problems. Problem behaviour is thus often 'labelled' to fit a stigmatised view of mental illness.
- ◆ Services offered to people with psychiatric disability have separatist intentions and are too strongly influenced by medical model interpretations of need. Services that have been developed to promote the participation of disabled people in work are usually separated from main stream work contexts, for example hospital-based vocational rehabilitation programmes, sheltered employment or protected employment.

1.6. Disability, unemployment and no-work - the size of the problem

Findings generated by surveys looking to enumerate the prevalence of psychiatric disability will be influenced by respondents' willingness to disclose and their interpretation of the concepts used in such surveys. Census surveys are not ideal because they generally do not allow for privacy, sensitivity or sufficient time required when dealing with matters as personal as disability. The data collected in Census 2001 indicated that 2 255 982 South Africans were living with various forms of disability; 5% of the total population enumerated in this census. The question used to determine the prevalence of disability was framed in such a way as to expand the concept of 'disabled' from a narrow focus on impairment to a broader focus that included human

functioning in a social context. The question was: "Does the person have any serious disability that prevents his/her full participation in life activities?" Types of disabilities were classified as 'sight', 'hearing', 'communication', 'physical' 'intellectual' and 'emotional' (Statistics South Africa, 2005:8). The prevalence of emotional disability was found to be high at 16% (Statistics South Africa, 2005). This statistic might have been influenced by possible misunderstanding by respondents (or even enumerators) about what disability means in terms of the various types. However, similar prevalence rates were obtained in a major study undertaken to explore perceived health indicators in South Africa; the prevalence rate for emotional disability was estimated at 16.9% (Statistics South Africa, 2004b).

Outside South Africa, concerns about the prevalence of mental ill health have also been raised. Glozier reported that the prevalence of mental ill health at work seemed to be rising "both in terms of self report (as shown by comparing surveys of work related illnesses throughout the 1990s), and as a cause of absenteeism, long term sickness, and early retirement" (Glozier, 2002:714). De Vries and Wilkerson drew attention to the fact that the United Nations, the World Health Organisation and the World Bank considered the prevalence rate of neuro-psychiatric disorder (1 in 4 individuals worldwide) to be a serious public health crisis (De Vries and Wilkerson, 2003). They further estimated detection and treatment rates to be low, and less than 10% worldwide. This would mean that 500 million people are underserved (De Vries and Wilkerson, 2003). In the United States, 4.9 million people in the working age population (18-65) are occupationally disabled. An additional 6.1 million people have secondary work limitations restricting the kind or amount of work that they can perform (Armstrong and Lyth, 1999).

Herrman (Herrman, 2001) contextualised the calculations done by the World Health Organisation to reach the conclusion that the burden of mental illnesses constituted 10% of the global burden of disease, and that depression was expected to be one of the largest health problems worldwide by the year

2020. These calculations were informed by a new index to measure total health burden, namely disability adjusted life years (DALYs), which summarise ill health, disability and loss of life from identifiable diseases into a single numerical measure. The sum of all DALYs is understood to be the global burden of disease. Mental health problems account for 8.1% of the global burden (De Vries and Wilkerson, 2003). Neuro psychiatric disorders are believed to account for more than one-quarter of the years of life lived with disability (De Vries and Wilkerson, 2003). Herrman concluded that the problems of mental health were increasingly a threat to the quality of life, to the economy, and to public health throughout the world (Herrman, 2001). De Vries and Wilkerson agreed, highlighting two global problems that are converging at this time, namely the escalation of neuro-psychiatric disorders and “an increasing dependence on mental faculties of the world’s citizens” (De Vries and Wilkerson, 2003:44).

In her argument for an increased focus on mental health promotion, Herrman put forward several points to explain the very low priority that mental health seems to be given world wide. Firstly, she attributed this to stigma and poor understanding of mental health and illness and secondly, to problems with health statistics. She shared her belief that the death rates resulting from mental illness conditions were greatly underestimated with the result that the disease burden was also underestimated (Herrman, 2001).

The disadvantage experienced by disabled people has prevailed despite government efforts to bring redress:

“In spite of the fact that attention has been appropriately drawn to the need to put into place structures, policies and strategies that promote the social inclusion of disabled persons, minimal success has been achieved” (Statistics South Africa, 2005:17).

The INDS records the alarming statistic that 99% of people with disabilities in South Africa are not formally employed (Office of the Deputy President T. M.

Mbeki, 1997). Employment figures for disabled people in the 2002-2003 Commission for Employment Equity Annual Report remained unchanged at 1% (Department of Labour, 2004). Similarly, a report commissioned by the Office on the Status of Disabled Persons found that 2% of employees across all 18 government departments were disabled (Research Dynamics South Africa, 2000).

A very different picture was presented in the Census 2001 report on Disability Prevalence in South Africa (Statistics South Africa, 2005). Significantly better employment figures are shown in Table I. The definition used for 'employment' in the 2001 Census is a broad one; it was "those who performed work for pay, profit or family gain in the seven days prior to the survey interview for at least one hour, or who were absent from work during these seven days, but did have some form of work to which to return" (Statistics South Africa, 2005:31). The term unemployed was used to indicate "those people within the economically active population who: (a) did not work during the seven days prior to the interview, (b) want to work and are available to start work within two weeks of the interview, and (c) have taken active steps to look for work or to start some form of self employment in the four weeks prior to the interview" (Statistics South Africa, 2005:31). The employment rate reported in the 2001 Census Report therefore fits comfortably with the use of 'work' in this study (rather than 'employment').

Table I: Percentage of disabled and non-disabled population that was employed in 2001 per age group

Age group (years)	Disabled people	Non-disabled people	Total
15-19	2,5	3,9	3,9
20-24	12,5	22,0	21,7
25-29	21,0	39,6	38,9
30-34	25,2	49,0	47,9
35-39	25,9	52,2	50,8
40-44	25,7	53,5	51,7
45-49	24,8	51,7	49,5
50-54	21,2	46,8	44,3
55-59	16,6	37,9	35,5
60-65	8,7	19,3	18,0
Total	18,6	34,6	33,7

The employment rate for disabled people was only about 19% compared to 35% of non-disabled persons. The disadvantaged position of disabled people was ascribed to (Statistics South Africa, 2005);

- ◆ diverse socio-economic and social cultural factors, particularly low levels of education, and
- ◆ discrimination in the labour market and negative attitudes of those they live amongst.

About 30% of disabled people had received no education while only 13% of the non-disabled population fell into this category. People with a post-secondary education had the lowest disability prevalence (3%) compared with the level amongst those who had no schooling (10,5%), had a primary level education (5,2%) or a secondary level of education (3,9%) (Statistics South Africa, 2005).

Employment and unemployment figures from the 2001 Census specifically for the Western Province, presented in Figure II, revealed a lower unemployment rate than for the rest of the country.

Figure II: Unemployment figures for the Western Province

Province	Total					
	Total	Not Economically active	Economically active			
			Total	Workers	Unemployed	Rate
	N(1 000)					%
RSA	29 305	9 578	19 726	11 643	8 083	41.0
Western Cape	3 147	851	2 296	1 691	604	26.3

High unemployment figures in South Africa affect countless non-disabled and disabled people alike; many who want and need to work are excluded from employment. Unemployment rose from 17% of the adult population in 1994 to almost 30% by 2001 (Higson-Smith, Richter and Altman, 2004). A large proportion of people in South Africa were therefore excluded from work. In 2001 10.8 million people worked, as compared to 4.5 million who were unemployed and actively seeking work. A further 3.2 million people were estimated as having given up the attempt to find employment despite the fact that they wanted to work (Higson-Smith et al., 2004). The 2004 Labour Force Survey pegged unemployment at 27.9% (Statistics South Africa, 2004a); again the official definition was used.

This situation could explain the attitude of indifference that has prevailed concerning people with psychiatric impairment who are unemployed, even when they have an expressed need to work. A high incidence of unemployment would naturally erode the ideal that all who want to benefit from work should necessarily be able to do so. Care should, however, be taken to ensure that barriers imposed by the constraints of the macro South African context, including high unemployment figures, do not mask discrimination against disabled people.

De Vries and Wilkerson found the “continuing inattention to mental health” to be “neither justifiable nor tolerable” (De Vries and Wilkerson, 2003:45) and rejected the claim that there were no treatments or that available treatments

were too costly. They contended that impressive and cost-effective treatment and prevention was available and that success of such treatment was high.

1.7. International conceptualisation of psychiatric disability and work

Research findings indicated that people with psychiatric disability have had to confront many barriers in their attempts to participate in the world of work (Blankertz and Robinson, 1996). Numerous barriers at human, family, organisational and societal levels have made it difficult for people with mental illness to secure and maintain work in accordance with their own needs (Moglowisky and Rumrill, 1996; Rutman, 1994; Johnstone, 2001; Herrman, 2001). Many would agree with Marrone and colleagues who concluded that people with psychiatric disability were discriminated against more overtly than those with other disabilities, particularly with regards to being hired for a job (Marrone et al., 1995). Researchers and service providers alike have emphasized the many problems that were experienced as a direct, or indirect, result of stigma. These include reduced self esteem and a tendency to withdraw (Link et al., 2001), shame and embarrassment (Kaas, 2001), reluctance to seek help (Brown and Bradley, 2002; Kaas, 2001), reduced compliance with medication (Sirey, Bruce, Alexopoulos, Perlick, Friedman and Meyers, 2001), problems with social adaptation (Perlick, Rosenheck, Clarkin, Sirey, Salahi, Struening and Link, 2001), and the knowledge that people in general considered them to be dangerous (Crisp, Gelder, Rix, Meltzer and Rowlands, 2000; Brown and Bradley, 2002). The prevalence and impact of stigma has been summarised by Johnstone as follows:

“Mental ill-health — and its profound stigmatization — carries with it a burden of human suffering that at times is not only incalculable, but incomprehensible to non-afflicted onlookers. Its consequences to both the sufferers of mental ill-health and their families/friends can be

deeply dehumanizing, culturally dispossessing and radically alienating. This, in turn, can perpetuate a most cruel injustice, notably, the denial of the mentally ill's moral entitlements to the things that other so-called 'normal' persons may take for granted: function, a sense of place in an intersubjective world, empathic connection with reciprocating others, peace of mind, happiness, participatory citizenship" (Johnstone, 2001:200).

Conclusion

This chapter introduced the argument of this thesis and offered a brief overview of the study. The next chapter will outline the context of the study in order to explain the current influences on the lives of people with psychiatric disability and to situate the findings.

Chapter 2: CONTEXTUAL FACTORS AND CONCEPTUAL ISSUES

Introduction

In this chapter a range of different contextual realities and conceptual explanations will be offered in order to situate the findings of the study. Contextual³ detail will be provided to explain the prominence given to transformation as a mechanism to counteract the inequalities that prevail in South Africa because of the lasting consequences of *apartheid* policies. The impact of new legislation that was promulgated soon after the democratisation of the country will be considered because of its potential to assist with equalisation of work opportunities for disabled people. The relative neglect of service provision in the field of psychiatry will be explicated to illustrate a medical bias and the lack of follow through into natural contexts.

An overview will be given of prominent policies that set the scene for a new era in which disability, as a human rights issue, will be viewed from the perspective of the social model of disability. However, translation of legislation and health policies for occupational therapy practice was required to show how occupational therapists might broaden their focus to address the occurrence of occupational injustice; something that has high prevalence amongst people with psychiatric disability. The impact that influences belonging to macro and meso dimensions ultimately have on work opportunities of people with psychiatric impairment will therefore be conceptualised.

³ In this study, the concept of environment is used interchangeably with context and means 'all those settings (physical, emotional, geographic or cultural) within which the action took place'.

In the final two sections of the chapter influences that are closer to the individual will receive consideration when the importance of stigma and conceptualisations of identity are explored. Consideration of these constructs is necessary to situate the methodology, to focus the findings of the study and to provide the conceptual foundation for the last two chapters.

2.1. The South African context

The South African context brings with it a complex interplay of influences that impact differently on designated groups of people. Most notable would be the lasting impact of colonialisation and of apartheid. The resulting contrasts, that characterise South African society, are at play in every domain of civic life.

2.1.1. Lasting influence of apartheid

The life of every South African is touched in one way or another by the legacy of our past, thus the impact of historical forces on current employment patterns and prevailing inequality will be explored here. Inequality which for the most part came about as the result of colonialisation was entrenched through the social engineering of the *apartheid* era. Opportunities were made available according to racial categories that were constructed for this purpose. Prospects available to the different racial groups, who grew up and lived separately from one another, were of different quantity, quality and variety. Apartheid legislation shaped the social, cultural and physical environments in which people lived, learned, worked and socialised. Political and economic structures together with societal institutions were used as trappings for the implementation of discrimination and inequality. The poverty that resulted from marginalisation and discrimination brought further restriction and inequality. People who were born into communities that were characterised by unemployment and poverty had lower quality school

education, restricted choice for tertiary education and faced limited career options.

Much has changed, but gross inequality still characterises South African society and much will have to be done to alter this. The impetus for transformation that is focussed on the achievement of redress, often through affirmative action, has become a major driver for new legislation and policies that seek to govern all societal structures. Such activities have positively shaped the lives of many South Africans belonging to groups that were designated for redress, namely black people and women. However, very little progress has been made to change the situation for disabled people (also one of the designated groups). Some explanation for this relative neglect of disabled people was given in the Commission for Employment Equity Annual Report for 2002-2003 (Department of Labour, 2004); that the priority given to disability equity has been overshadowed by other pressing concerns in our new and growing democracy. The functioning of crucial social institutions has been stretched by old and new challenges, including ongoing and often increasing inequality, national reconciliation, regional migration, globalisation and the HIV and AIDS pandemic (Department of Labour, 2004).

Specific evidence of prevailing inequality is to be found in the health services available to people with psychiatric disabilities. Although segregation along racial lines is something of the past, availability and access to services are determined by class and by location. A relatively good range of services within reasonable distance is available to people with the means to afford health insurance. In comparison, only the most basic services, often with poor access, is available to communities in urban and peri-urban areas. Non governmental organisation (NGO) services complement government services for uninsured populations; these services have however been fragmented with unpredictable and random conditions affording access. It is within this context that re-dress and equity are important government imperatives.

2.1.2. Health care provision

One of the main political drivers of the current government is the redress and equalisation of service delivery across all provinces and for all its citizens. Health systems, including psychiatric services, have been undergoing transformation since the democratisation of the country in 1994. Services were previously fragmented along racial lines, concentrated in urban areas and overwhelmingly hospital-based. Large institutions offered excellent care to small groups of people in the larger cities while only rudimentary care was available in surrounding rural areas.

Restructuring of all health services has been the focus of the new South African government and transformation is the main driver of policies designed to redress inequality. The aim of the national Department of Health is to provide accessible, equitable, adequate and appropriate mental health services (Gagliano, 1995). Such reforms are considered to be a political imperative but also a moral right (Freeman, 1998). The present move is towards establishing community-based services, with the integration of mental health services into primary health care (Emsley, 2001). Ultimately, public health services should meet health needs within integrated, comprehensive health programmes. This implies a balance between curative, promotive, preventive and rehabilitative programmes that are positioned at tertiary level, secondary level or primary-level, respectively. The government's commitment to provide 'health for all' favours a decentralised approach in which primary health care workers will play a major role (Gagliano, 1995). The realisation of a comprehensive mental health approach, including prevention and promotion, has however been hampered by budgetary constraints (leading to the problems mentioned above). Resources for health care provision are allocated in fierce competition with other essential services, for example housing, education and safety. Within the available budget for health care, priorities such as HIV/Aids and tuberculosis outweigh the needs of people with psychiatric impairments.

Freeman (1998) warned that the Health Department is expected to provide comprehensive mental health services with the same budget that was available to the old dispensation and from which the majority of South Africans received extremely poor mental health services (Freeman, 1998:742). However, the Department of Health's commitment to improve service delivery was confirmed by Freeman who wrote the following in an Editorial to the South African Medical Journal:

"The Minister of Health and those of us working in mental health planning and policy at national and provincial levels recognise that mental health services are not satisfactory. However, there is a strong commitment to mental health change from government and positive developments are taking place" (Freeman, 1998:742).

Integration of mental health into mainstream health provision is overdue. The large clinical loads and inadequate training that primary health care workers receive in psychiatry contribute to a situation in which patients with psychiatric disorders are not being identified and treated (Emsley, 2001). The current situation in 2005 is such that curative services are biased towards short-term emergency services for patients who are experiencing relapse or who pose a danger to themselves or others. At primary level most provinces have a wide network of clinics focussed on pharmacological maintenance for secondary prevention. Of concern is the fact that treatment programmes, other than pharmacological intervention, are non-existent for most. Specialised programmes, including vocational rehabilitation, are based in a small number of tertiary hospitals in the large cities. Private practice settings or non-governmental organisations (NGOs) broaden the scope of services to include more sophisticated modalities such as rehabilitation units for substance dependency, a range of focussed counselling services, life skills training, individual therapy and support groups. Related services, such as group homes, protected and sheltered work environments are also made available in the NGO sector. Access to these programmes is unfortunately

limited to those able to afford private health services or people fortunate enough to be affiliated to an NGO.

The scope of services provided

The inequalities that characterise health service delivery are shown by the limited scope of services available to people with psychiatric disability. Current service delivery in South Africa is dominated by short-term management of relapse or emergency. The dominance of medical model strategies, without any support during the crucial phase in which natural life spaces are re-entered, is a major limitation. Service provision beyond discharge is limited to monthly visits to a clinic where a psychiatrically trained registered nurse will oversee the administration of medication and consider the need for hospitalisation when necessary. The large numbers of clients for whom nurses are responsible prevent their broader involvement with issues beyond clinical maintenance and the management of emergencies (Gagiano, 1995). For these reasons services offered to people with psychiatric disability should be extended beyond what is currently available.

Herrman advocated for a broader focus for mental health services (Herrman, 2001). She warned that practitioners often underestimated the scope of mental health promotion or prevention because of their predominantly clinical focus, and also that those responsible for a broad interpretation of the mental health needs of populations tend to feel daunted by the task. Herrman believed that:

“Politicians and educators may not understand the effects of their work on mental health, nor have access to relevant information, or equally likely, have to set priorities which exclude health promoting measures. Once the community grasps the relationship between social conditions and mental health, politicians and educators will be able and encouraged to act.” (Herrman, 2001:713).

2.1.3. National policies designed to promote equity

Integrated National Disability Strategy

The Integrated National Disability Strategy (INDS) (Office of the Deputy President T. M. Mbeki, 1997) has as its foundation the new South African Constitution that was adopted in 1996. Chapter 2 of the Constitution guarantees fundamental rights to all citizens, and Section 9 promises the right to freedom from discrimination based on a number of social criteria, including disability (Research Dynamics South Africa, 2000). The United Nations Standard Rules on the Equalization of Opportunities further informed the development of the INDS for Persons with Disabilities. The involvement of people with disabilities in the process of transformation was adopted as the key principle by disabled people's movements. Other essential aspects are:

- ◆ Endorsement of the principles of the social model of disability as a mechanism to move away from medical and welfare interpretations of disability.
- ◆ Acknowledgement of a strong relationship between disability and poverty, stating that poverty makes people more vulnerable to disability while disability reinforces and deepens poverty.
- ◆ Identification of people with severe mental disabilities as one of the traditionally disadvantaged groups in South Africa.
- ◆ Repositioning of disability as a human rights issue. This resulted in an acknowledgement of the premise proposed by the social model for disability, that, if society cannot cater for people with disabilities, it is society that must change.

The ultimate goal of the INDS is for people with disabilities to play a full, participatory role in society. This is important for people with disabilities because it is a break from traditional views such as the medical model or the welfare model. The social model operates from a human rights perspective that insists on the right of disabled people to participate in an integrated society. Its goal is to development a barrier-free society for all. The INDS

indicates that the need for support of people mental disabilities has been recognised, despite the fact that fully integrated services do not yet exist.

The Disability Rights Charter of South Africa

The Disability Rights Unit of Lawyers for Human Rights together with Disabled People South Africa (DPSA) worked on a charter of the demands of disabled people in South Africa. This process was started in 1991 and involved a lengthy process of consultation with many organisations of disabled people throughout the country, before the DPSA Council finally adopted it in December 1992. The Disability Rights Charter of South Africa aims to promote equal opportunities for all disabled people. It asserts the right of all disabled people to live independently in a safe environment, free from all forms of discrimination, exploitation and abuse (Research Dynamics South Africa, 2000). This charter, developed by disabled people, for disabled people, demonstrates the political impetus for protection of disabled people's rights. Through this charter disabled people lay claim to the fulfilment of their rights; it demonstrates clearly the political power of the disability movement.

The spirit of redress and social justice, which characterise these policy documents, makes the present research relevant. These policies should, in the long term, shape the transformation of health care provision.

2.1.4. Provincial policies developed to guide practice

Psychosocial Rehabilitation Policy

The purpose for development of a policy guideline for psychosocial rehabilitation (PSR) was to provide a framework for the development of psychosocial rehabilitation in the Western Cape Province. It was envisaged that the PSR policy would shape service provision in order to facilitate

recovery in four life areas, namely living, working, socialising and learning. The PSR policy has a broad and ambitious vision to promote the creation of 'a society for all' through the creation of optimal opportunities for integration of mental health consumers within the communities in which they live. However, the principles and objectives contained in the policy reveal a narrow focus on service provision without consideration of the needs of people within context. The policy has a medical model interpretation of rehabilitation. In other words, the policy is concerned with service provision without due consideration of promotion of participation or equalisation of opportunities outside the service network.

2.1.5. International policies underpinning local policies

Standard Rules on the Equalisation of Opportunities for Persons with Disabilities

The Standard Rules for the Equalisation of Opportunities for Disabled Persons were drafted to provide governments with guidelines about how this can be achieved. The United Nations (UN) facilitated this process and the Standard Rules were finally adopted in 1993. The UN Standard Rules ask for a strong moral and political commitment by the State. They guide policy-making and action to ensure that persons with disabilities may exercise the same rights and obligations as other citizens. The Objectives of the Standard Rules were captured in the INDS as follows:

- ◆ to stress that all action in the field of disability presupposes adequate knowledge and experience of the conditions and special needs of persons with disabilities,
- ◆ to emphasise that the process through which every aspect of the organisation of society is made accessible to all as a basic objective of socio-economic development,

- ◆ to outline crucial aspects of social policies in the field of disability, including, as appropriate, the active encouragement of technical and economic cooperation,
- ◆ to provide models for the political decision-making process required for the attainment of equal opportunities, bearing in mind widely differing technical and economic levels and the fact that the process must reflect not only a keen understanding of the cultural context within which it takes place, but also the crucial role of persons with disabilities in it, and
- ◆ to propose national mechanisms for close collaboration among states, the organs of the UN system, other intergovernmental bodies and organisations of persons with disabilities.

The Standard Rules are good because they provide clear guidelines, set standards and point out how to prevent discriminatory practices with an integrated approach. They provide a framework for disabled and non-disabled people alike. The impact of this is international uniformity and a standard against which countries can measure their own disability policies. South African conditions do not yet comply with the recommendations set out in the Standard Rules although the principles have been incorporated into legislation.

2.1.6. Legislation designed to promote equity

Achievement of equity in South Africa is the strong focus of new legislation. Four legislative pieces were considered to be pertinent to the study because, together, these promise to bring about a significant increase in employment opportunities for disabled people.

Basic Conditions of Employment Act of 1997: Since its adoption disabled people are less at risk of exploitation because basic conditions of employment have been stipulated. Employees and job-seekers are protected against unfair

discrimination based on their disability, particularly with regard to unjust dismissal and hiring.

Skills Development Act of 1998: The Skills Development Act of 1998 promulgated tax incentives for employers who employ disabled people. Money allocated specifically for skills development, including learnerships, will stimulate training opportunities for disabled people through Sector Education Training Authorities (SETAs).

Employment Equity Act of 1998 (EEA): The EEA places emphasis on employment equity, it also legislates affirmative action strategies “to redress the disadvantages in employment experienced in the past, including people with disabilities” (Silver and Koopman, 2000:23). Medium and large companies are now expected to employ people with disabilities; financial advantages have been put in place to reward employers who comply with recommendations to employ disabled people (Silver and Koopman, 2000).

Code of Good Practice (2001): The Code of Good Practice, that was developed to guide the implementation of the EEA, provides a foundation for the development of affirmative action initiatives and for the implementation of reasonable accommodation.

However, six years after the adoption of the EEA, the situation is much the same for disabled people as before its adoption, suggesting that legislation alone is not sufficient to achieve equity. Particular emphasis should be given to affirmative programmes that are developed to facilitate the entry and the maintained participation of people with disability in the world of work. Research, such as the present study, is required to inform the development of such programmes.

2.2. The world of work

The availability of work opportunities are believed to be directly linked with broader economic environments. Opportunities for the employment of people with disabilities are therefore similarly depended on economic growth, the overall rate of employment and the availability of labour (Boardman, Grove, Perkins and Shepherd, 2003a). For many years the South African economy was stifled, restricted and hindered in its development, in part because of sanctions that were imposed on the *apartheid* government. Job creation is one of the priorities of the South African government in their attempt to reduce poverty. Attempts are made to achieve higher employment levels, broader types and availability of work, the achievement of employment equity and skills training (Research Dynamics South Africa, 2000).

The income divide between rich and poor in South Africa continues to be the focus of much concern. Steps taken to normalise the situation have included affirmative action strategies in the workplace and designated 'black economic empowerment' initiatives; mixed successes have been achieved but the economic divide between rich and poor has prevailed. For example, market trends revealed that the number of people who are not economically active increased gradually over time, from 12,8 million in 1995 to 13,5 million in 1999 (Statistics South Africa, 2001).

Consideration has been given to pertinent issues that impact on social cohesion⁴ which is considered an essential element for healthy and sustained

⁴ As a descriptive term, *social cohesion* refers the extent to which a society is coherent, united and functional, providing an environment within which its citizens can flourish. Department of Arts and Culture (2004) Social Cohesion and Social Justice in South Africa: A Report by the Social Cohesion and Integration Research Programme. Human Sciences Research Council.

development in South Africa. These issues have direct relevance in terms of the social inclusion of disabled people;

- ◆ Economic behaviour is embedded within social relations and the wheels that drive the economy are oiled by activities and transactions that are based on cooperation (Department of Arts and Culture, 2004:48). Good relationships and cooperation are essential ingredients of the types of work relationships that will allow for the integration of disabled people in the work force and the South African economy.
- ◆ Asset redistribution, based on the assumption that equity improves economic performance and that greater equality tends to promote efficiency. Persistent racial, class, gender and generational inequalities do not only undermine meaningful forms of cooperation, but also create deep social divisions and erode social cohesion" (Department of Arts and Culture, 2004:49). Disabled people belong to a marginalised group that continues to be left behind in terms equal opportunities.
- ◆ Exceptionally high unemployment rate (42% in 2005) is one of the most striking features of the South African labour market. "With the present focus on redressing the legacies of apartheid, the extent to which unemployment entrenches historic inequalities is troubling" (Department of Arts and Culture, 2004:50).
- ◆ Employment equity has been a major focal point and will continue to be a concern whilst inequalities prevail. Racial and gender inequalities (i.e. white and male) persist in the more skilled and managerial occupations; even though African, Coloureds and Indians constitute the majority of the total workforce. Disability equity has not shown much improvement at all.

2.2.1. Social consequences of non-participation in work

People who do not work, for whatever reason, are often discriminated against. Negative attributes, such as uselessness and dependence on others

are often assigned to those who do not work (Jones, 1993). Conversely, those who do work are assigned more worth because value and status is assigned according to the work that people do. The devastation of unemployment is closely tied with associated financial hardship and the inability to meet related needs. Social benefits (in the form of financial grants) are very limited in South Africa, for example:

- ◆ Unemployment insurance benefits are restricted to employees who had made contributions to the Unemployment Insurance Fund. Coverage is offered, for a limited period of time (6 months), to those who are newly out of work. Both employers and employees are required by law to contribute one percent of wages (paid and earned) to the Unemployment Insurance Fund.
- ◆ Disability grants are available to disabled people whose health condition/impairment and activity limitations are such that they are unable to work. Such a judgement has to be made by health professionals, often a medical practitioner, without consideration of the work preferences or the availability for work.

A strong correlation therefore exists between being unemployed and being poor because work is the only viable and sustainable source of income. In South Africa almost 50% of the population are considered to be poor or at risk of becoming poor (Watson and Fourie, 2004a). These contextual realities mean that people who are prevented from participation in work, because of barriers confronted as a result of psychiatric disability, in fact, carry a double burden, namely unemployment and psychiatric disability.

The growth rate in South Africa has remained consistent, but low, between 2% and 3% of the gross domestic product for the first decade of democracy. In addition, employment in the formal sector has stagnated, and that of growth in the informal sector has begun to slow down (Higson-Smith et al., 2004). Given the current unemployment levels, neither economic growth, nor the overall rate of employment can be relied on to alleviate the problem. The

problem of unemployment is further complicated for people with disabilities by stigma that has resulted in discrimination.

“Widespread ignorance, fear and stereotypes cause people with disabilities to be unfairly discriminated against in society and in employment. As a result, people with disabilities experience high unemployment levels and, in the workplace, often remain in low status jobs and earn lower than average remuneration” (Department of Labour, 2001:4).

2.2.2. The value of participation in work

The economic disadvantage of unemployment has a significant impact on health, quality of life and community participation. While alleviation of poverty is an obvious advantage when work is obtained, the concurrent realisation of human potential should not be underestimated. Employment could halt or reverse the disabling process experienced by mental health service users (Boardman et al., 2003a)..Jones argued that work was central to “all economic and social life and probably to the human condition itself” (Jones, 1993:11). He considered paid employment to be the main source of valuable commodities including;

- ◆ income for quality of life,
- ◆ identity for self-esteem and social confidence and
- ◆ meaningful activity, for feeling useful and avoiding boredom.

Unemployment, on the other hand, “is identified with rejection, uselessness, dependence on others, poverty, deprivation, the sense that the value of one’s own personal time moves towards zero, and the elimination of power to make significant personal choices” (Jones, 1993:11). Lobo (1999) explained that unemployment enforced un-obligated free time, or free time that was not earned, as discretionary free time usually was, which can lead to feelings of guilt. Reduced income further restricted the choice of activities in which

unemployed people were able to participate. Lobo also differentiated between un-obligated free time, imposed by joblessness, and the same resulting from leisure time; leisure includes notions of freedom, choice, inner compulsion towards activity and pleasure. She concluded that leisure and unemployment were incompatible (Lobo, 1999). Boardman et al agreed and stated:

“Being ‘in work’ has important implications for the personal well-being, social status and civil rights of those with mental illness, as well as for their use of health and social services. Work offers considerable personal and economic benefits for users of mental health services” (Boardman et al., 2003a:467).

Research has shown that engagement in work activity can have a therapeutic effect (Moglowky and Rumrill, 1996, Polak, 1996 #66, Lehman, 2002 #121; Boardman et al., 2003a) and also “an ameliorating effect on symptoms over time” (Bell and Lysaker, 1995:508). By improving economic independence practical needs were met through involvement in work (Lehman, Goldberg, Dixon, McNary, Postrado, Hackman and McDonnell, 2002). This assumption is embedded not only in the practice of occupational therapy (Steward, 1997; Pratt, McFadyen, Hall, Campbell and McLay, 1997; Strong, 1998), but also that of other rehabilitation professionals (Blankertz and Robinson, 1996; Krupa, 1998). Participation in work allows for social inclusion, and gives people with mental illness opportunities to participate in society as active citizens (Boardman et al., 2003a). Work often plays a role in the way people define themselves, and gauge their own value and that of others around them (Strong, 1998). Again, Boardman et al. agreed with the positive consequences of work:

“Enabling people to retain or gain employment has a profound effect on more life domains than almost any other medical or social intervention” (Boardman et al., 2003a:467).

Linn, Sandifer and Stein demonstrated a definite relationship between health and employment in their prospective study (N=300) undertaken to explore

the impact of stress on health (Linn, Sandifer and Stein, 1985). Men who became unemployed during the six months study (n=30) were compared with an equal number (matched for age and race) who continued to work. Multivariate analysis of variance and covariance revealed significantly greater occurrences of somatization, depression and anxiety in the unemployed group when compared to the employed group. This group also made significantly more visits to their physicians, used more medication and spent more days sick in bed. A large standard deviation (13.2) for self-esteem in the unemployed group indicated that some men coped better than others with job-loss stress. Those with better self-esteem scores were found to have more support from family and friends. The results strongly suggested that unemployment had an adverse impact on psychological function that, in turn, often manifested in the form of physical symptoms and heightened worry about these.

Marrone concluded a discussion in which he considered the consequences of work and unemployment for people with psychiatric disability with a clear statement that unemployment is much worse for mental health than the stresses of employment (Marrone, 1999).

“No hard data exist showing that helping people move into employment (even nagging them into it) is bad.. ..Issues that unemployment, particularly long-term unemployment, brings to the fore are depression, feelings of worthlessness, self-pity, self-absorption, higher risk of substance abuse, greater chance of isolation, and poverty” (Marrone, 1999).

It is not without an appreciation of the ill-effects that the notion of work has brought to modern societies, (Paterniti, Niedhammer, Lang and Consoli, 2002; Stanfeld, 2002) that a case is made for work being health promoting. Furthermore, consideration should be given to the personal differences and individualised needs of people. Care should be taken not to generalise beliefs

about the value of work to disabled people as a group, without sufficient attention to individualised interests and varying need to participate in work.

2.3. Occupational science as a core framework

Occupational science offers a useful and dynamic framework for analysis, descriptive language and strategies with which to conceptualise the consequences of participation, or non-participation, of disabled people in work and other domains of civic life. Whilst an occupational science viewpoint is an obvious one for occupational therapists to take, its potential to unite the efforts of rehabilitation professionals, disabled people's organisations and policy makers has been underplayed. An argument is made here that health service activities could be united and their impact maximised if 'participation in occupation'⁵ is adopted as a shared outcome for diverse service efforts. Occupational science provides the theoretical foundation for understanding occupational justice and injustice and formed the basic premise for the concerns raised at the outset of this study.

Yerxa introduced occupational science as follows:

"Occupational science is a basic science devoted to the study of the human as an occupational being. As a basic science it is free to pursue the widest and deepest questions concerning human beings as actors who adapt to the challenges of their environments via the use of skill and capacities organized or categorized as occupation" (Yerxa, 1993:5).

She emphasised that it was a basic science and she made the point that occupational science could not be "constrained in its development by preconceptions of how its knowledge will be applied in occupational therapy clinical practice" (Yerxa, 1993:5). Yerxa addressed "a major question

⁵ Occupation refers to a full range of activities categorised as work, leisure and personal life skills.

confronting societies” when she asked the question “What is the relationship between human engagement in a daily round of activity (such as work, play, rest and sleep) and the quality of life people experience including their healthfulness” (Yerxa, 1993:3). This question lies at the heart of occupational science. It suggests a focus for occupational therapy i.e. the restoration of occupational engagement and implies a concern for people who have reduced opportunities to participate in occupation due to macro contextual influences such as high unemployment. These would include limited access to education, discrimination (including gender restrictions) or inequality and deprivation (including issues associated with living in poverty). Yerxa considered the fact that many occupational therapists still “practice in hospitals and clinics in which the traditional medical view of illness and disability predominates” (Yerxa, 1993:4) to be a dilemma because “the profession may not be fully achieving its rich potential in making a difference in people’s lives” (Yerxa, 1993:4). Because the medical model’s priority concern is the alleviation of symptoms, it often brings with it a limit in focus that does not include the occupational engagement of people within their natural contexts. Certainly, those people whose healthfulness or quality of life is reduced by influences other than chronic impairment or disability would not be the concern of occupational therapists practicing in traditional settings. Occupational science could provide a vehicle to broaden the scope of occupational therapy practice through its concern to better understand occupation in domains outside traditional practice settings.

Duncan (Duncan, 2004) made a strong case for the incorporation of occupation as a mechanism through which mental health could best be promoted. She contended that “productive occupation and the desire to engage purposefully and meaningfully with a range of life experiences is a hallmark of mental health” (Duncan, 2004:201). This understanding was based on work by Wilcock (Wilcock, 1998) who situated humans as occupational beings who relied on participation in occupation as a “fundamental mechanism by which people realize aspirations, satisfy needs

and cope with the environment because it provides the mechanism for the maintenance and growth of physical, mental and social capacities” (Wilcock, 1998:110).

2.3.1. Occupational injustice

Occupational therapists hold the view that people have a natural drive to meet their fundamental needs through participation in occupation (Watson and Fourie, 2004b). They therefore accept the prominence of occupation as the single most important mechanism through which people meet a variety of different needs. Occupational science poses the challenge, provides the language and offers opportunities for other professionals and non-professionals jointly optimise the participation of disabled people in occupation. By positioning problems associated with disability according to their impact on the achievement of occupational justice, diverse approaches could be united to work towards a shared outcome. If the power of occupation to fulfil people’s needs is accepted, it would follow that the availability of occupation to all who wish to participate in it is an important consideration.

Occupational justice “is about recognising and providing for the occupational needs of individuals and communities as part of a fair and empowering society” (Wilcock and Townsend, 2000:84). When peoples’ occupational engagement is prevented by a set of external limitations on the choices and/or opportunities, occupational injustice will be the result. The stigma associated with psychiatric disability causes the type of exclusion that leads to occupational injustice, particularly in an environment where opportunities for occupational engagement are further limited by resource constraints. Occupational injustice can be counteracted through recognition of the occupational nature and needs of people and through the creation of policies

“that allow people’s occupational nature and need to flourish” (Wilcock and Townsend, 2000:84).

The ease with which mainstream society, including many rehabilitation professionals, accept psychiatrically disabled people’s exclusion from work, often because of attitudinal barriers, is a source of injustice. Prejudice dominates every time a generalisation is made that somebody with a psychiatric impairment is not able to cope as a worker, without sufficient scrutiny of the validity of such a belief. Research evidence presented in Chapter 3 will show many predictors of the ability to work that are regularly used, such as severity of symptoms, to be unreliable. It is argued here that the same social action, which will ensure equal participation in work, will also combat occupational injustice.

Alleviation of occupational injustice will be guided by a thorough knowledge of occupational science; it facilitates service developments across all systems levels and comprehensive programmes. It is concerned with participation in occupation within natural life-spaces. One advantage of taking an occupational justice perspective is that it “provides materiality to relatively abstract concepts like ‘social justice’” (Swartz, Duncan, Watson and Clarke, 2004:347). Whilst humans participate in occupations as autonomous agents such participation is interdependent and contextual (Swartz et al., 2004). Contextual realities in environments that are characterised by poverty usually carry the risk of occupational injustice. When disability is superimposed on people who are already vulnerable, occupational injustice would almost certainly be found to be a problem. Employment statistics and current prevailing stigma and prejudice are indicators of the risk of occupational injustice. It follows that people with psychiatric disability are even more at risk of experiencing occupational injustice than other disabled people.

“Occupations are human pursuits that, at best, fulfil people’s needs and wants. They have the transformational power to bring about

development and maturation across multiple transitions when the choices and processes are personally meaningful” (Watson and Fourie, 2004b:19)

2.4. Disability as a social construct

Cook and Burke (Cook and Burke, 2002) suggested there was a ‘sea change’ that positively affected public policy, legislation and political power that set the stage for participation and integration of disabled people. Such changes were the combined result of several social movements, which led to new models of disability that allows for “a more comprehensive understanding of the place of people with disabilities in the labor market and, especially, labor force dynamics for people with disabilities. This involves acknowledging that people with disabilities are both similar to and different from those without disabilities in their labor force attachment, experiences, and decision-making” (Cook and Burke, 2002:543).

No attempt can be made to define comprehensively concepts such as psychiatric impairment and psychiatric disability, without addressing the complexities that necessarily have to be explored in order to comprehensively present a multitude of views and opinions. Turner identified a relative scientific neglect of disability studies that changed in the 1980s with the growth of the disability movement and the quest for social rights (Turner, 2001). An important outcome of the disability movement is the recognition of an ideology of ‘able-ism’ that is operationalised in exclusionary social values and functions (Turner, 2001).

“Throughout Western history, disability has existed at the intersection between the particular demands of a given impairment, society’s interpretation of that impairment, and the larger political and economic context of disability (Braddock and Parish, 2001:11).

2.4.1. The social model of disability

Disability activists who were active in the disability movement developed the social model of disability. It inverted the understanding of disability by arguing that "it was not impairment that was the main cause of the social exclusion of disabled people but the way society responded to people with impairments" (Oliver, 2004:19). The social model shifted the focus away from functional limitations of the individual with an impairment towards the problems caused by disabling environments, barriers and cultures (Oliver, 2004).

"Disability is a form of social oppression and the social model highlights both social oppression and social understanding in relation to disability" (Beresford, 2004:214).

The participation of people with psychiatric disability in the disability movement has been late in coming; they remain on the margins of the disability movement even today. Beresford (2004) summarised recent developments in the service user/survivor movement in the United Kingdom. His very careful use of terminology signalled the sensitivity required to include activists who disagree on important points. Some activists prefer the term survivor; a shorthand for 'psychiatric system survivor'. This term denotes people's survival of the mental health services, rather than survival of the mental illness. Other activists prefer the term service user, a more passive term that is thought to be used by people who are less radical and less critical in their stance against current systems, services, policies and the dominance of psychiatry (Beresford, 2004; Barnes and Shardlow, 1996).

The possible incorporation of the service user/survivor movement into the ideas of the social model of disability has been considered. Discussions

around what the social model of madness and distress would look like are at an initial stage (Beresford, 2004). Beresford explained that for service users/survivors to be integrated into the social model of disability, transformation of the existing model would be required; the reason he gave was that many survivors are not willing to see 'impairment' as an objective part of their condition. He also cautioned against approaching discussions to advance on the social model from a different perspective with a simplistic understanding of the social model (Beresford, 2004).

The core element of arguments by critics, who call for the rejection of the social model of disability, is its conceptual separation of impairment from disability. They reject the claim that society alone is the cause of disability and propose that impairments do play some role in causing disability (Thomas, 2004).

2.4.2. The nature of psychiatric disability

Mulvany (Mulvany, 2000) introduced a discussion about the nature of psychiatric disability within the Social Model of Disability by highlighting sociology's neglect:

"Sociological theory and research has not provided either a much-needed analysis and critique of the major changes taking place in mental health policy or fostered any recent social policy directed towards improving the quality of life for people diagnosed as suffering from severe mental illness who live in the community" (Mulvany, 2000:583).

Two contributions highlighted by Mulvany were that of labelling theorists and the members of the anti-psychiatry movement; these are however described as "often crude and unsophisticated" (Mulvany, 2000:583).

Similar ideas were shared in an earlier article by Goldstein who reviewed sociology research, highlighting the limitations of medical model interpretations of mental illness that were identified by researchers who preferred to take a sociological interpretation instead (Goldstein, 1979). The demonstrated impact of social and political influences on mental illness served as evidence for this assertion: "Since the 1950s empirical research has consistently shown both an inverse association between mental illness and social class, and a direct association between mental illness and being female and/or unmarried" (Goldstein, 1979:384). Labelling theory (of which the central hypotheses was attributed to Scheff) was hailed as a major contribution of sociology to understanding mental illness:

"Scheff saw mental illness arising from the breaking of the nameless residual rules of social life. Such norm violations, mostly unrecorded and of transitory significance, arise in many ways and are prevalent in society. When a residual rule breaker is publicly labelled as mentally ill, a stereotype of mental illness, learned in early childhood and continuously reinforced, may be applied to the individual" (Goldstein, 1979:387).

Critiques of the labelling theory include that it was not a theory in the strictest sense, a lack of certainty about the degree of validity with which this perspective would deny that actual deviant behaviour has occurred and the evasion of the existence of primary deviance. Goldstein highlighted that "very little is known about the specific mechanisms by which social factors influence the incidence of mental illness" (Goldstein, 1979:391). He mentioned stress, sex and marital status and social support systems as possibilities.

Mulvany called for sociologists to re-visit the study of serious mental disorder and suggested that a direction forward could be found in the writings of disability theorists despite a concern that disability theorists "have rarely included psychiatric disability in their work" (Mulvany, 2000:584). A point was made that new vigour and direction might be given through application of the

social approach to disability to the study of mental ill health. This because of its potential to orient "research and theoretical development towards an analysis of the complexity and multiplicity of the social restrictions faced by people diagnosed as 'mentally ill', and the social disadvantage and oppression they face" (Mulvany, 2000:585).

An important objective of mental health user groups, "whose identity and 'problems' have been defined by professionals" (Barnes and Shardlow, 1996:114), has been to reclaim the right to self definition; in other words, to define themselves and their problems. This process has however been problematised by the risk of stigma when the status as user of mental health service become visible (Barnes and Shardlow, 1996). Barnes and Shardlow considered factors that affect identity construction processes for people who experienced mental health problems (Barnes and Shardlow, 1996). They highlighted personal and inter-personal factors, explaining that the nature of mental distress may itself undermine a person's sense of self-identity.

Psychiatric disability is a hidden disability. Fitzgerald and Paterson (1995) used the term "hidden disability" rather than "invisible disability" to indicate the choice that people have to keep their impairments hidden in order to manage their illness identities (Fitzgerald and Paterson, 1995:15). They describe the meaning of the term hidden disability as "those disabilities (impairments or handicaps) which are not easily seen, measured, or objectified" and "those which lack external features or visible signs" (Fitzgerald and Paterson, 1995:15). The issue of disclosure becomes pertinent.

Mulvany explored the issue of disclosure and strategies that facilitate disclosure. A conclusion was drawn that many consumers are afraid to disclose their experience; in part because of negative stereotypes that are perpetuated through beliefs and behaviour as well as through the media (Mulvany, 2000). Consumers are often afraid that if they disclose before

employment they may not be hired and if they disclose once employed promotion might be withheld, supervisors might have a negative expectation or be afraid to give honest feedback. In balancing these negatives against disclosing, the benefits could be that consumers are free to be themselves and relieved of stress caused by concealing a significant part of themselves from their co-workers and supervisors. Once the consumer has disclosed however, she is eligible to request for reasonable accommodations (Mulvany, 2000).

2.4.3. The impact of regional cultures on disability concepts

The already complex interrelationship between culture and psychiatry is more problematic in the South African context where constructions of difference were over-emphasised and developed into racial categorisation to serve the interests of a minority group at the expense of the majority. Although it falls beyond the scope of this thesis to provide a comprehensive exploration of the interrelatedness between culture and psychiatric impairment, some discussion is needed to contextualise the experiences of participants captured in the findings. The concept culture has been described as “the process of being and becoming a social being, about the rules of a society and the ways in which these are enacted, experienced, and transmitted” (Swartz, 1998:7). Some constructs that are relevant to psychiatry, for example self, adaptation, adjustment and bodily processes, are therefore closely related to culture. These concepts do not only have biological meaning, they also have social and cultural meaning (Moldavsky, 2004).

Young provided an overview of Anthropology’s interest in sickness and Medicine, summarising the gradual emergence of a distinctive anthropological discourse on sickness (Young, 1982). He identified new professional opportunities that he believed originated (1) in the efforts of clinicians who had grown dissatisfied with biological reductionism and (2) in the high level of

economic support available in the United States. Young explained that anthropologists have three distinct ways of writing about sickness and healing:

- ◆ Medical beliefs and practices were described using conceptual systems which were originally intended for studying other phenomenological domains.
- ◆ Methodologies and conceptualizations were borrowed from medical sociology.
- ◆ Using a conceptual system centred on the social and experiential particularities of sickness and healing.

The first two approaches were deemed problematic for a number of reasons that will not be explored here. The third was considered to be the best methodology for anthropologists to use.

Swartz contrasted universalism, evolutionism and relativism as paradigms of understanding that shaped and explained differences in views held about culture and mental illness.

- ◆ **Universalism:** "...mental illness is universal, and that our job in looking cross-culturally is to find evidence for these universals" (Swartz, 1998:12).
- ◆ **Evolutionism:** "... alien idea systems not only are truly different from our own, but are different in a special way; viz., other people's systems of ideas are really incipient and less adequate stages in the development of our own understandings" (Swartz, 1989:84).
- ◆ **Relativism:** "... alien idea systems, while fundamentally different from our own, display an internal coherency which, on the one hand, can be understood but, on the other hand, cannot be judged" (Swartz, 1989:84).

Swartz applied the fundamental assumption of universalism to mean that the concepts of mental health and illness were universally the same. He suggested two reasons why the true nature of universal illnesses might be

obscured; “first, the way we *label* conditions in different settings, and second, how conditions are expressed in different cultures” (Swartz, 1998:12). This understanding stood in strong contrast to notions of relativism. The incompatibility of a radical relativist stance in practice contexts, wherein a clinician has to make decisions based on categories of desired and undesired behaviour, becomes clear. However, Swartz highlighted a potential disadvantage of a relativist approach, namely the desire to stay true to context, which might mean loss of the larger perspective.

Concepts of disability are culturally imbedded and affect the way people with disability perceive themselves and the world around them. Similarly, the views and behaviour of non-disabled people will be shaped by their construction of disability, which in turn are shaped by cultural beliefs and practices (Grace, 2001). The knowledge of cultural interpretations of disability and beliefs that impact on people with disability is an important consideration for those who develop programmes for disabled people. “Such knowledge can help establish what is universally true about disability and what is unique to specific cultures” (Grace, 2001:5). Grace believed the acceptability of different types of disability to be closely tied to explanations of the appearance of that specific type of disability. In other words, the social expectations placed on individuals of a particular cultural group, once they reach adulthood, will determine the level of acceptance experienced by people with particular disabilities.

Moldavsky explained the mechanisms through which culture relates to health in the following way:

“Culture influences psychopathology through pathways like stresses, chronic social conditions (e.g., poverty, deprivation), protective factors, modulation and promotion of change, tolerance for particular behaviours, and sanction of specific idioms of distress” (Moldavsky, 2004:36).

Grace warned that when traditional beliefs and practices are studied, care should be taken not to view socio-cultural beliefs as 'static' (Grace, 2001). Despite the fact that many traditions and beliefs about disability has been "exceptionally long-standing" and "intricately interwoven into many aspects of the local cultural belief system" (Grace, 2001:7), belief systems change over time. Western ideas and modernization trends of regional and national contexts have led to change occurring more rapidly (Grace, 2001). Swartz (1998) agreed, and warned that the image held of the anthropologist that goes out to view strange, exotic cultures that have not been in contact with other cultures was seriously outdated.

The experiences of participants in the present study required the lenses of universalism and relativism to be fully understood. Their life stories were situated in a changing environment in which traditional beliefs still held, while new views and understandings are incorporated.

2.5. Psychiatric disability as a stigmatised social construct.

The barriers that disabled people face in the workplace include physical obstacles, as well as systemic barriers to employment, and attitudinal barriers (Silver and Koopman, 2000). Silver and Koopman singled out attitudinal barriers as the most difficult to overcome. They speculate that ignorance, fear, misunderstanding or hate contribute to attitudes that keep people from "appreciating and experiencing the full potential of a person with a disability" (Silver and Koopman, 2000:79). In an opinion piece Johnstone (Johnstone, 2001) called health professionals to action in processes that would help alleviate the negative consequences of mental illness for disabled people and their families. She conceptualised the problem as follows:

"People suffering from mental illness and other mental health problems are among the most stigmatised, discriminated against, marginalized, disadvantaged and vulnerable members of society. Although much has

been done in recent years to improve the status quo, it is evident that a great deal more needs to be done to improve the moral standing of and to achieve social justice for the mentally ill" (Johnstone, 2001:200).

It has been my experience in the field of psychiatry that most consumers of psychiatric services anticipate negative prejudice and discrimination. Secrecy, a mechanism to protect against anticipated stigma, characterised the experience of most. Goffman described the process of stigmatisation as one that originated from the need to group people into categories developed for the purpose of bringing a sense of order to our social environments (Goffman, 1963). Such categorisations could bring a sense of containment that was based on the elements of familiarity and predictability. Unfortunately it also provided a foundation for stigmatisation of those that fell outside categories that were well known, or as Goffman stated:

"While the stranger is present before us, evidence can arise of his possessing an attribute that makes him different from others in the category of persons available for him to be, and of a less desirable kind – in the extreme, a person who is quite thoroughly bad, or dangerous, or weak. He is thus reduced in our minds from a whole and usual person to a tainted, discounted one. Such an attribute is a stigma, especially when its discrediting effect is very extensive; sometimes it is also called a failing, a shortcoming, a handicap (Goffman, 1963:2).

Additional damage is done when a member belonging to a stigmatised group, e.g. people with mental illness, internalises the faulty attributes that were assigned by, mostly uninformed, members of society. Goffman (1963) differentiated between what he termed "the discredited" and "the discreditable" (Goffman, 1963:4). He described the discredited as stigmatised people who assumed that their differentness was already known. Discreditable people, on the other hand, assumed that their differentness was not known or perceivable. Goffman held that stigmatised people displayed a

defensive response to their situation. They might see both the defect and the response as retribution for something that they themselves, their parents or their tribe had done. They therefore considered the treatment they received as justified.

Questions have been posed about the role stigmatisation ultimately plays in the illness experience of people. The Modified Labelling Theory was developed to explain how people with psychiatric impairment would come to fear rejection, in part, because of their own views before they first experienced illness. They are influenced by their sense of what others might think of them, therefore becoming timid and acting without the confidence employers might be looking for in an employee (Link, 1982). Negative consequences are therefore believed to be the direct result of being given a negative label through a process explained below.

“In the course of being socialized, individuals develop negative conceptions of what it means to be a mental patient and thus form beliefs about how others will view and then treat someone in that status. Typically this array of beliefs is fully in place before an individual enters treatment. As a result, when patients enter treatment for the first time, they are likely to confront the effects of stigma immediately because often they have internalised a generally negative view about what it means to be a mental patient. Moreover, they tend to endorse coping orientations such as secrecy, withdrawal, and education. With time, their beliefs about the implication of the label they carry and their way of dealing with it shape the nature of their social connectedness” (Link, Cullen, Struening, Shrout and Dohrenwend, 1989:419).

Link used empirical research to test the labelling hypothesis and found that labels do have negative effects on various aspects of an individual's life (Link, 1982). He went as far as to assign a partial role to labeling in the etiology of

disorder; particularly in the stabilisation or maintenance of deviance. A series of reinforcing conditions are believed to emphasise consequences of a negative label in ways that might serve to “increase environmental stresses such as job loss or rejection by would-be marriage partners, reduce access to social supports, and generate a tentativeness and lack of confidence that undermines an individual’s usual means of coping” (Link, 1982:13).

Based on the expectation that stigma associated with mental illness could bring a significant loss of self-esteem, Link, Struening Neese-Todd, Asmussen, and Phelan set out to investigate evidence for such an association. They accepted the argument proposed by ‘modified labelling theory’, which explained how the negative conceptions of mental illness, developed early in life, formed the basis on which people with psychiatric disability come to expect rejection (Link et al., 2001). Club members affiliated to a clubhouse programme (modelled on the Fountain House model) were randomly assigned to a non-intervention control group or an intervention group designed to facilitate coping with stigma. Measurements of self-esteem (using the Rosenberg scale), stigma (measured with a 12 item instrument that captured anticipated stigma) and stigma-withdrawal (using a 9-item instrument that assessed the extent to which withdrawal was considered to be the solution for stigma) was done. The intervention did not have a measurable effect on participants’ perceptions of stigma, depressive symptoms or self-esteem. However, the findings revealed that stigma strongly influenced the self-esteem of people who had mental illness. The authors concluded that the magnitude of the association between stigma and self-esteem was startling and disturbing (Link et al., 2001).

The fact that people with mental illness could look, or act, in ways that are considered ‘odd’ contributes to their stigmatisation (Marrone et al., 1995). Another contributing factor was thought to be the media’s portrayal of images that link mental illness with the tendency to be aggressive or dangerous (Marrone et al., 1995). Brown and Bradley agreed that the inaccurate and

unfavourable portrayal of mental illness in the media contributes to the stigma associated with having a psychiatric impairment (Brown and Bradley, 2002).

Wolpert wrote a personal account of the stigma he experienced when he was hospitalised and treated for depression (Wolpert, 2001). Most noteworthy might be Wolpert's realisation that he himself stigmatised illnesses with a psychological basis:

"I did not think that there was any psychological basis for my depression though my wife thought otherwise. I very much preferred a biological explanation. This is probably because then I was not really responsible for the condition, it was like a physical rather than a mental illness. It was not unlike having a diagnosis of post-traumatic stress disorder, which carries no stigma because the cause is so clearly an external one. But what then was my problem with a psychological basis for the depression? I have had to come to accept that I too stigmatise depression when the basis is psychological and that my public declarations that depression is a serious illness and should carry no stigma are not as honest as I would like them to be" (Wolpert, 2001:221).

Conceptualisations of stigma and research that concentrates on the processes of stigmatisation and institutionalisation has been identified as an influential stream of work that deserves attention in conventional sociology of health and illness. However, sociology has been criticised as contributing "surprisingly little in terms of systematic theory and research to the study of disability" (Turner, 2001:252).

Goffman's contribution has led to much debate around the central question whether or not his approach involved a cynical assumption that there is no true or continuous self, "only an endless and playful presentation of masks" (Turner, 2001). Susman described Goffman's classic work on stigma as a "rich

exposition of causes, forms, and effects of stigma in American society” (Susman, 1994:16) before summarising criticisms of his work. She highlighted criticisms by Hahn and Anspach that Goffman’s deviance approach conveyed and perpetuated the idea that disabled people are inevitably passive and victimised. Another criticism by the same authors concerned the relative lack of emphasis on political dimensions of disability. Susman defended the second criticism by explaining that Goffman did foresee the likelihood of disabled people organising and gaining recognition as a political group rather than a stigmatised group and by highlighting that his work was specific to the 1950 context (Susman, 1994). Another point of contention about Goffman’s deviance approach was that it was too inclusive a category that encompassed voluntary and involuntary conditions, for example murderers and epileptics. An alternative anthropology concept, namely ‘liminality’ was suggested as an alternative when referring to disability (Susman, 1994).

Camp, Finlay and Lyons questioned the assumption made by others (Link et al., 2001) that belonging to a stigmatised group would necessarily lead to a reduction in self-esteem. They conducted a qualitative study, avoiding the use of global measures of self-esteem that fail to allow detailed investigation of the relationship between ascribed identities and the self-concept (Camp, Finlay and Lyons, 2002). Findings revealed that participants were critical and pragmatic in their acceptance or rejection of labels. They rejected those labels perceived to carry an unrealistic and negative stereotype, or those they did not identify with as fitting with their diagnostic criteria. The research illustrated the importance of considering people’s subjective understandings of stigmatised conditions and societal reactions in order to understand the impact of stigma. The sampling method used in this study, a convenience sample that was taken from a group of women who attended a user-led centre for women, was limiting. I would argue that a purposive sample that ensured variation would have been preferable (Camp et al., 2002). Susman (Susman, 1994) also mentioned that the work of several authors showed that disabled people are not inevitably socially devalued or excluded. The reasons

for this was given as (1) variation in culturally shared responses to impairment across time and social context and (2) new ways of thinking about the meaning of disability that allows for greater acceptance.

2.6. Explicating conceptions of identity

The dominant role of self-identity⁶ in decisions made about participation was immediately evident in the early stages of the research. The findings, which will be presented in chapters to follow, showed influences that hindered or promoted participation in work to be linked to processes of identity construction. It was therefore necessary to explore constructs of 'self' or 'identity' in order to situate the findings. Work by Christiansen, a prominent occupational therapy scholar who studied identity and occupation, pointed to the use of Baumeister's ideas (Christiansen, 2000; Christiansen, 1999; Christiansen, Little and Backman, 1998). However, a lack of fit with between Baumeister's construction of identity and the findings obtained in this study suggested the need for a more fluid interpretation of identity. This led to an exploration of Munro's ideas that will be introduced in this chapter (Munro, 2004).

The findings will show how closely participants' identities were tied in with perceptions of their own acceptability in immediate (meso) environments, for example work environments and/or family contexts, and in broader society (macro environment). Societal views and the perceived attitude of significant people in participants' lives had a clearly discernable shaping influence on identity construction processes that influenced participation in work and other social spheres. Questions therefore arose around constructs of 'dependence' and 'interdependence', both being evident in the experiences of participants in this study. Shutte's ideas were explored and will be presented here

⁶ The term is used when reference is made to the body of theories on 'self' and 'identity'.

because they offered answers that placed individual identity construction processes in the context of others' (Shutte, 1993). Brief attention will also be given to Denzin's forms of self and Polkinghorne's realms of reality in order to facilitate understanding of the methodology used in this study.

Considerations by Casey were explored because they situated discourses of the self in the context of work. Her consideration of the self as "a product of collective moral beliefs and behaviour" (Casey, 1995:66); something that was historically produced and that is affected by transformation of social order⁷, mirrored the findings obtained in this study – particularly the role that work seemed to play in managing identity.

2.6.1. Identity constructs underlying the methodology

Earlier in the chapter some attention was given to Denzin's understanding of the consciousness of a person as consisting of the inner and the outer worlds. The inner, or phenomenological stream of consciousness "describes the person caught up in thoughts and the flow of inner experience" (Denzin, 1989:28). The outer, or interactional stream, "locates the person in the world of others" (Denzin, 1989:28). Denzin distinguished five forms of self; the phenomenological, the linguistic, the material (or self-as-commodity), the self-as-ideological subject, and the self-as-desire (Denzin, 1989:31). Polkinghorne held the view that human existence consists of a stratified system with differently organised realms of reality. These were the material realm, the organic realm, and the mental realm was also briefly introduced (Polkinghorne, 1995).

⁷ Casey focussed on industrialization, the influence of which has impacted in South Africa. The dominant macro influences currently in South Africa are transformation and equalising of opportunities. A new social order, strongly shaped by processes of democratisation and equalisation, is prominently impacting on the identities of South African workers.

2.6.2. Identity constructs that conceptualised findings

As a point of departure Baumeister's ideas were explored, this was done because of the prominent use of Baumeister in occupational therapy literature (Christiansen, 2000). Baumeister formulated ideas of the self that were in keeping with modernist theories that are based on continuity of the self, in fact, continuity was understood to be one of two criteria for a stable identity. He described identity as "a definition, and interpretation, of the self" (Baumeister, 1986:4) and contended that:

"Identities exist only in societies, which define and organize them. Thus, the search for identity includes the question of what is the proper relationship of the individual to society as a whole" (Baumeister, 1986:5).

Baumeister acknowledged the ideas of David Hume and Immanuel Kant in his own thinking. Hume understood the self to be the mind and its contents. Every time new contents entered the mind, it was changed with a resultant change in the self. He believed the totality of the self changed and became a different one as the contents of the mind changed. His argument was thus that the self is something we are not able to know directly and that the concept of identity is therefore a fictitious one (Baumeister, 1986). Kant agreed with Hume that the self is not able to perceive itself directly. He understood the self to be the perceiver, not the perceived. However, he believed that the self is able to catch itself in the act of doing something. Through the ability of the self to catch itself in the act of doing something self-consciousness is created. Thus, the self is not known in isolation or by itself. The self is always and only known in relation to the world. Self-awareness is a superimposed awareness (Baumeister, 1986:13). Kant's thinking did however include the existence of the pure, real self that actually existed without being known directly to anyone; known as the 'noumenal self'. The noumenal self was proposed by Kant to make possible the 'phenomenal self', which is the self that appears in conscious experience (Baumeister, 1986).

Two important concepts, adapted from Kant's ideas, form the basis of Baumeister's ideas. First, it is easy not to know the self because the self cannot be known directly but can only be glimpsed in action (that is, can only be noticed in the process of doing something else). The "phenomenal self" is inferred or deduced from other perceptions or cognitions. Second, the unity of the self over time (crucial to any notion or model of identity) is not guaranteed or built-in but is rather created. "The self is such an elusive thing because it is merely inferred from other experiences and is *somehow* stitched together across time" (Baumeister, 1986:14) (italics in original).

Baumeister adopted Dilthey's definition for experience; that is "any event or collection of events with a unity of meaning" (Baumeister, 1986:14). An experience could therefore comprise happenings that are strung together across time, even if these are not temporally continuous. The significance of this definition of experience is its resolution of Hume's paradox. "If the experience spreads across time, and the self is derived (known) from experiences, then the self too can begin to have unity across time" (Baumeister, 1986:15). Herein lies the key to understanding the link between doing and identity, and in a society in which participation in work is endowed with strong assessments of worth, the impact on identity is a major one.

Thus, experiences could be sets of events that are spread out across time and united by a common meaning. If knowledge of self is derived from experiences, then it too can be spread out across time. Moreover, unity of meaning seems important in producing unity of identity. Baumeister therefore concluded that a sense of identity was dependent on meaning and because meaning occurs within a contextual network of relationships, a final conclusion drawn was that "*identity is a linguistic construction*" (Baumeister, 1986:15) (italics in original).

Baumeister proposed two defining criteria that ensured the development of a stable identity:

- ◆ Continuity. "Continuity is a special case of unity, unity across time; it entails being the same person today as yesterday or last year or next week. One's sense of identity is strengthened by things that require one to be the same person across time" (Baumeister, 1986:18). One example of an activity that would facilitate continuity is making promises.
- ◆ Differentiation. "Differentiation entails being different from others. One's identity must contain some elements that distinguish it from others" (Baumeister, 1986:18).

Baumeister believed that 'fulfilment' and 'potentialities' are closely linked and that an identity that contains a well-defined sense of potential "is more than just having an idea of something one could do. It is having a belief that personal fulfilment can be achieved by doing that something. The potentiality aspect encompasses identity's actual and possible goals" (Baumeister, 1986:20). *Components* of identity were understood to be basic types of self-definition and with each identity containing an indefinite number of components. These components were organised into five different category-types according to the way each identity component is acquired;

- ◆ Type I components are assigned; the person does not have to do anything to acquire identity components that belong to this category. One example is gender. Type I self-definition is therefore passive, stable and unproblematic. Baumeister carefully explained that he meant 'unproblematic' to apply specifically and exclusively to the acquisition of an identity component and not the responsibilities or influences associated with such a component. Achieving identity component types is increasingly problematic from the first level to the fifth level.

- ◆ Type II identity components are acquired through a single transformation, for example motherhood. Once the transformed identity component state is reached, it is stable and unproblematic.
- ◆ Type III self-definition is based on a hierarchy of criteria with a comparable set of distinctions; the amount of wealth accrued serves as a good example. If one earned a particular amount, it is also possible to earn some more. Type III self-definition is problematic in that it is never clearly achieved, it furthermore provides grounds for comparison and competition. Type III self-definition is not problematic in so far as criteria and procedures for the achievement of such criteria are concerned.
- ◆ Type IV and V types of self-definition are about types of choices made rather than achievements. The differentiation between type IV and V is made to allow for a distinction between choices that are optional (Type IV) and those that are required (Type V). Baumeister used a choice between Catholic and Protestant faith to illustrate these types of self-definition. An adult who encounters Christianity for the first time will be required to choose between the Catholicism and Protestantism, this would resemble Type V processes. However, a child growing up in a religious home will not be required to make such a choice. Another example of Type V self-definition is the choice of career a person chooses to pursue from a large number of diverse and incompatible options. Type V choices occur without clear rules or structure to guide such decisions. In other words, society expects of people to make 'the right' decision by looking 'within' themselves to where the self is expected to contain the answers. Baumeister believed that the identity contains values or priorities of preference that could guide such choices; he referred to these as metacriteria. Metacriteria are relied on to generate answers.

Explanation for the emergence of identity problems

Baumeister (1986) drew on the two defining criteria of identity he proposed in his model namely continuity (unity) and differentiation to explain the cause of identity problems. "If the components fail to provide continuity and differentiation, then the individual will lack a stable identity" (Baumeister, 1986:122). He also proposed two processes by which components have been rendered ineffective in producing identity. The first process, *destabilization* is described as "the failure of the *unifying* function of the identity component" (italics in original) (Baumeister, 1986:122). Baumeister (1986) argued that the way one defined the self provided continuity only if it remained the same throughout life, if the component of identity changed, the unity of self over the lifetime would be lost. Baumeister further explained that actual change is not necessary to weaken the ability of a component to define identity, possible change or expected change could separate the present and future self from the past self. The second process, *trivialisation*, was defined by Baumeister (1986) to mean "the failure of the *differentiating* function of the identity component" (Baumeister, 1986:122).

When an attempt is made to understand fulfilment, the question of potentiality comes to mind "for it is one's potentiality that is fulfilled. The need for persons to create their own meanings of life has led to a concern with how to discover and cultivate potentiality in order to achieve fulfilment" (Baumeister, 1986:157).

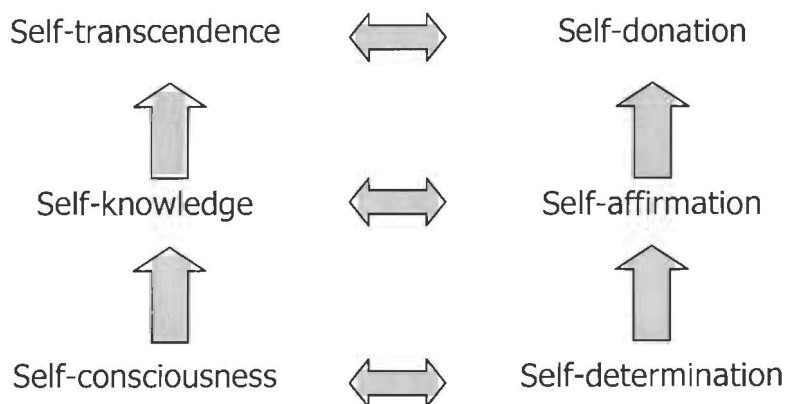
Baumeister's construct of identity was similar to Denzin's construct of a person in that both emphasised the interrelatedness of identity and society. Pertinent differences, relevant to this study, were the formulation of a 'stable identity' and the structured societal structures that suggest predictable interference to the continuation of identity. Shutte's philosophy of the self shared an emphasis placed on the interrelatedness of self and society, but without the same emphasis on individuality.

2.6.3. Situating ideas by Shutte within the context of the study

Shutte anchored his ideas on two points of similarity between contemporary Thomist philosophy and traditional African thought. These are firstly, that “human persons transcend the realm of the merely material” (Shutte, 1993:9) and secondly, that people need to be empowered by others in order to develop. He attempted to show how the paradox of freedom-in-dependence expresses an important truth about human nature. He proposed that “it is precisely our capacity for free self-realisation that requires *a certain kind* of influence of other person if it is to develop towards fulfilment” (Shutte, 1993:10) (italics in original). Shutte described this development through three stages: “from the basic capacity for self-consciousness and self-determination that makes us persons, through increasing self-knowledge and self-affirmation, to a progressively greater ability for self-transcendence and self-donation in our relationship with others” (Shutte, 1993:10).

It was certainly not only the African participants in the study for whom Shutte’s ideas seemed to apply. Linkages with significant community members formed a foundation for self-determination.

Figure 2.1: Pictorial presentation of Shutte’s ideas



Post modern philosophers such as Derrida, Foucault, Lacan Lyotard, Baudrillard and Kristeva have had a strong influence on social and cultural theory in the West; this influence, and also that of the American philosopher Rorty, prompted a departure from modern or humanist views of self. Modern views of the self were criticised for the tendency to portray the self as “a fixed, irreducible, “solid” entity – the essential core of one’s being” (Casey, 1995:3)

Casey tracked the influence of symbolic interactionism on ‘self’ and ‘identity’ starting with Charles Horton Cooley’s concept of the ‘looking-glass self’⁸, then George Herbert Mead’s expansion of this concept to explain the emergence of the self-concept in social interaction as an outgrowth of the person’s concern about how others react to her (Casey, 1995). Mead understood each individual to have as many selves as she has social roles and saw social interaction as a necessary condition for the emergence of the self. Erving Goffman’s comparison of social interaction to a drama, in which each person must ‘act’ to shape others’ view of themselves as competent and performing a legitimate role, developed a view of social life as something that is somewhat amorphous and instantaneous. “An important implication of the theatrical analogy of interaction is that people do not have any central reality or ‘self’ beyond the performance they present for others” (Casey, 1995:58). The legacy of social interactionist theorists is an understanding of the ‘self’ as a ‘process’ rather than a ‘system of mechanisms and needs’. ‘Identity’ was understood to be a psycho-social process; the sociological equivalent of the concept of ‘self’ which relies on integration into a particular social system (Casey, 1995).

⁸ A concept that refers to the individual perceiving herself in ways that others perceive her (Casey, 1995)

The main criticism of social psychology is its neglect of broader social dimension; attention is focussed on the 'self' and the social interactions within the family or immediate social group.

2.6.4. Punctualized identity

Munro (Munro, 2004) proposed the idea of identity being *punctualized*: a "revealing of each specified identity within the here and now; and in response to the 'demand' of others" (Munro, 2004:294). An acceptance of Munro's idea would therefore imply that each person has the potential to reveal identities that would fit the demands of an 'other'. In other words, identities 'stand in reserve, ready to be revealed when 'called forth' by the demands of others in specific situations. Munro also argued for the *positioning* effect, suggesting that a viewer should be 'locked in' a particular standpoint to make a specific reading of identity. The *timing* effect was explained to mean that "each 'call' demands a display of identity that annuls other 'calls' – precisely by overtaking these in the here and now" (Munro, 2004:294). The ideas contained in *punctualizing identity* offered a solution to the much-contested notion of multiple identities that coexist, or the ideas of selves that freely inhabit social spaces. Instead the timing with which identities were revealed would mean that the one overtakes the other in the here and now (Munro, 2004). Four concepts come into play in Munro's model, these were;

- ◆ Revealing (or material extension): Identities are revealed in many different ways; and also by the effect of materials in the form of 'belongings'.
- ◆ Setting-upon (or elicitation): Munro used Heidegger's phrase 'set-upon' to explain how other people have the power to elicit particular identities in complex ways, which would include the power that the other has.
- ◆ Challenging forth (Ordering Identities): This notion was based on Heidegger's 'challenging forth'; it affects relationships and identities. To

understand this, the concept enframing, a translation of Heidegger's *Gestell*, should be considered. Enframing orders self-revealing as a kind of 'standing-reserve'. Munro explained that "within enframing, identity is punctualized: people stand 'on call', ready to produce an appropriate identity whenever it is challenged forth" (Munro, 2004:298).

- ◆ Setting upon (Elicitation): This was the last condition in which Munro explained the condition through which an order is elicited or called forth.

Martin Heidegger was instrumental in the development of existential phenomenology, which examines the relationship between phenomena and individual consciousness. He proposed a science of the non-objectifiable, unspeakable grounds of experience; a view in which the human being is understood to be derived from the categories of its own facticity as a finite, situated historical being grounded in its life towards death (Phillips, 2005). Heidegger's focus during early teachings of a new form of phenomenology was on *Dasein*⁹ which means "being here" or 'being there' – also explained as 'the existing human being as a someone who is placed somewhere and lives in a particular time' (Phillips, 2005). Particular aspects that are inherent in this explanation captured particular developments in Heidegger's thinking (Inwood, 1997):

- ◆ The being of humans was considered to be different from that of other entities because *Dasein* is an entity for which, in its Being, that Being is an issue; it has no definite essence - the essence of *Dasein* lies in its existence.
- ◆ *Dasein* is not a substance with an essential nature and with properties or 'accidents' and its potentiality or possibility is prior to its actuality, therefore *dasein* is not a definite actual thing, but the possibility of various ways of being.

⁹ *Da*, may mean here or there.

- ◆ *Dasein* is not so much about whether or not to be, but rather 'how to be' or 'how it is', and 'manner, mode, or way of being'. Important to note that *Dasein's* way of being involves the capacity to choose among several possible ways of being. Heidegger emphasised this character with his contention that *Dasein*, alone of all entities, exists or has existence; the verb *existieren* stem from Latin words meaning literally 'to stand forth' and 'standing forth'. It should therefore be understood that *dasein* stands forth, creating its own ways of being, in a way that no other entity does.
- ◆ Heidegger exploited the pronoun 'man' (in German, *das Man*), to mean the 'one' or the 'they' to also include myself (in so far as I do, think, and feel what 'they' do, think, and feel). In so far as the 'I' conforms to the 'they', the 'I' is not the individual self, but the 'they-self'. The self of everyday *dasein* is the they-self, which should be distinguished from the authentic self. Therefore *dasein* is inauthentic in so far as it does things simply because that is what one does; it is authentic in so far as it makes up its own mind, is its own person, or true to its own self.

2.6.5. Self within a diverse society

The authors of the Social Cohesion Report drew an interesting conclusion that "the sense of the sameness of a nation – nation building – relies on a sense of difference (Department of Arts and Culture, 2004). A sense of community is – counter-intuitively – produced in debate and disagreement" (Department of Arts and Culture, 2004:303). They applied this to people with disability in much the same way as to any other categories of difference. They contended that a sense of community arises as much out of shared disagreement as it does out of shared experience. "Without that sense of difference within sameness, there is no sameness and the disabled community in all its richness is really absent" (2000:303).

Conclusion

Inequality prevails despite a decade of democracy during which a strong commitment to redress was seen to be evident in affirmative action strategies that were designed to bring equity amongst all South Africans. My basic premise, foundational to this study, and in line with views that the natural trend amongst mental health professionals and the general population to underestimate the capacities and skills of psychiatrically disabled people and to over-estimate the risk to their employers. Realistic risks should however receive serious consideration, because of negative attitudes that result when people with psychiatric impairment fail in the workplace.

Answers to these questions, based on empirical evidence, are not easily found. In fact, answers are further complicated by the unpredictability of psychiatric impairment, with accompanying stereotyping, stigmatisation and misinformation. Literature presented in Chapter 3 will show that many variables, thought to be good predictors of psychiatrically disabled people's ability to succeed or fail at work, were found to have mixed predictive value.

Chapter 3: EXPLICATING INFLUENCES ON WELLBEING AND WORK OBTAINED FROM THE LITERATURE

Introduction

This chapter will explicate the findings of research undertaken to answer questions that are closely related to the question asked in this study. A review of the literature revealed a tendency to investigate the impact of possible relationship (mostly predictive) between a broad range of variables and the ability of people with psychiatric disability to work. In other words, micro influences, with emphasis on diagnostic categories and symptomatology, were scrutinised to reveal potentially predictive values that could determine work outcome.

An immediately obvious limitation of the research obtained lies in origins that are so different from the South African context that the relevance of findings has to be judged with great scepticism. There is a paucity of research produced in South Africa and no studies found that originated from contexts that are similar to the South African context. Most of the research reported originated from the United States and the United Kingdom with some from Canada and Australia and very few studies based in France and Japan. Research findings that were based on experiences of people with psychiatric disability in developed countries do not necessarily apply in South Africa or other developing countries where service provision and social support networks are different. For this reason a hand search was done of all South African journals in which research applied to psychiatric disability and work might have been published. This search comprised primarily occupational therapy and social work journals.

The main emphasis of research world wide related to people with psychiatric disability and work seemed to focus on curative strategies, mostly best

management of symptomatology. Three themes were found to be evident in the body of literature published around psychiatric disability and work. The primary focus was to discover the accuracy with which particular variables could be used to predict particular outcomes. A second focus was on measuring the effectiveness, and at time cost-effectiveness, of different types of vocational programmes. These designs often relied on a comparison between supported employment programmes and more traditional vocational rehabilitation programmes. A third, less dominant focus was descriptions of service programmes in the form of case studies. This last focus was, however, the dominant focus of South African publications, especially those articles found in occupational therapy and social work journals. The issue of stigma as a pertinent contextual reality associated with psychiatric disability was explored in opinion pieces and in research articles that measured the impact of stigmatisation. Other opinion pieces considered the relevance of broad policies or legislation, the wisdom of particular disability benefits or the priority given to psychiatric disability.

The body of literature published was dominated by quantitative studies within a positivist paradigm. Further, Honey concluded a literature review by highlighting that the voices of people with psychiatric disability (or consumers) were mostly absent from the research (Honey, 2000). She recommended that more qualitative research should be done to combat this tendency.

3.1. The effect of diagnosis and symptomatology on work capability

Published literature revealed a strong emphasis on research that measured the extent to which particular diagnostic categories, together with particular symptoms, influenced or predicted the success with which people with psychiatric impairment performed at work. What was also evident across the research were strong debates, with supporting research to contest opposing

sides, that focussed on answering questions about whether or not symptoms associated with psychiatric diagnoses influenced the ability to perform at work. Furthermore research seeking correlations between particular clusters of symptoms and finding employment, maintaining employment and efficacy of participation in employment (including the number of hours worked) was also found.

The outcome of the literature review in this thesis, as well as two other published reviews (Anthony, 1994; Honey, 2000) confirmed my personal experience that neither diagnostic categories nor particular symptoms provided a clear basis for predicting future work performance. Anthony discussed the outcome of five literature reviews that he undertook (with different colleagues), between 1976 and 1988, to investigate the relationship between clinical and demographic indicators and future vocational outcome. A similar conclusion was drawn by Cook and Pickett who thought much could be learned and better understood about the interaction of diagnosis, symptoms, skills, and job environment because important covariates such as psychiatric treatment status, individual abilities, prior job skills training, prior work history, rehabilitation services, and traditional labour force predictors should be better understood (Cook and Pickett, 94/95). Anthony summarised as follows:

“An intriguing aspect of previous research has been the findings with respect to what does not relate to vocational outcome. In particular, neither particular patterns of psychiatric symptomatology, psychiatric diagnoses, nor successes in other life domains correlates strongly with vocational outcome. A variety of studies have reported the lack of a relationship between future work performance and a variety of assessments of psychiatric symptomatology. There appear to be no symptoms or symptom patterns that are consistently related to individual work performance” (Anthony, 1994:3).

An earlier study by Rogers, Anthony, Toole and Brown contradicted other research in which symptoms were not found to be good predictors of work ability (Rogers, Anthony, Toole and Brown, 1991). In this study subjects who were married, experienced less severe symptoms and did not have a history of criminal justice involvement, had better outcomes in achieving vocational goals. Subjects (n=275) were newly assigned to one of three community-based vocational programmes, and had an expressed vocational goal. The sampling method therefore excluded hospitalised patients, some of whom might have had long-term treatment before their involvement in the study and patients who might not have been interested in work. Another study in which particular symptoms were found to predict the outcome had a similar sample, namely people with an expressed vocational goal. Bell and Lysaker (Bell and Lysaker, 1995) examined the relationship between psychiatric symptoms and work performance for 61 subjects with schizophrenia or schizoaffective disorder, who participated in a work rehabilitation programme. Subjects were placed in actual jobs where the Positive and Negative Syndrome Scale (PANSS) was subsequently used to measure symptoms in week 3 and week 13, and work performance was measured using the Work Personality Profile (WPP). The positive component of the PANSS failed to make predictions of performance. However, cognitive, negative and hostility components of the PANSS did reveal significant predictions (negative and cognitive dimensions being the most powerful). A conclusion was drawn that symptoms were found to have a direct impact on work capacity, particularly cognitive, negative, and hostility dimensions. Positive symptoms did not seem to have a significant impact.

Most researchers who set out to identify particular variables as strong predictors of ability to work have failed to do so. Anthony, Rogers, Cohen and Davies contextualised their study by discussing a range of studies in which neither the types of symptoms experienced by people with psychiatric impairment, nor their characteristics, were found to show a correlation with vocational outcome measurements (Anthony, Rogers, Cohen and Davies,

1995). In their study that examined a possible relationship between diagnosis, symptomatology, work skills and the future vocational performance of people with severe mental illness they found a moderate negative relationship (only 10-15% of variability) between ratings of symptoms and ratings of work skills. It is important to note that the subjects in this study (n=275) had expressed a vocational goal before intake into the study. Variables examined were: symptoms (measured by the Brief Psychiatric Rating Scale), diagnosis, work skills (measured by the Griffiths Work Behaviour Scale) and vocational status at end-point. The authors concluded that knowledge of psychopathology could provide only moderate evidence of a person's functional capacity to work. Hill investigated whether ratings of psychiatric symptoms can be used to predict future work outcomes (Hill, 2000). Participants (n=200), all categorised as severely mentally disabled, were assessed with the Brief Psychiatric Rating Scale before entering a programme comprising a pre-job development phase, a job development phase and a placement /employment support phase. Three outcome categories "successful outcome" (community employment at the time of case closure from the programme), "unsuccessful outcome" (cases closed in which the individual did not attain community employment during involvement in the programme), and "partially successful" (people who had attained employment during their involvement in the programme but for whatever reason were not working at the time of closure) were used. Hill concluded that the symptoms experienced by participants at intake into the study had no bearing on their employment outcome and should therefore not guide decisions about entry into community employment programs (Hill, 2000). Jones, Perkins and Born arrived at a similar conclusion in a study with a large sample (n=907) of supported employment participants with serious mental illness (Jones, Perkins and Born, 2001). None of the clinical or demographic variables analysed were significant predictors of work outcome or of the amount of supported employment services used. The variables scrutinised were Global Assessment of Functioning (GAF) score, age, number of lifetime hospitalisations, gender and whether or not participants had the diagnosis of

schizophrenia. Findings were particularly robust, due to the large and diverse sample of participants and the range of provider agencies that participated. The GAF score was not found to be a significant predictor of work outcome. This score is essentially a rating of overall functioning in domains of psychological, social and occupational functioning, based on the clinician's judgement (in this instance occupation refers to work). Findings therefore called into question the accuracy with which clinicians were able to judge the occupational functioning of participants (Jones et al., 2001).

Cognitive performance¹⁰ of people with psychiatric disability is arguably the aspect that would most regularly be the cause for concern when employment of people with psychiatric disability is considered. Such assumptions were tested in a carefully constructed study (Gold, Goldberg, McNary, Dixon and Lehman, 2002). A comprehensive battery of assessments was performed on all subjects in the context of a controlled clinical trial that compared the outcomes of two different vocational rehabilitation programmes. Subjects in this study were all diagnosed with DSMIV Axis I psychiatric impairments. Importantly, no differences were found in the baseline cognitive performance between the 40 patients who obtained employment and the 110 who remained unemployed at 24-month follow-up. However, cognitive performance was identified to be a predictor of job tenure because a better baseline cognitive performance was associated with the number of hours worked at 12 and 24 month follow-ups. The conclusions drawn about the predictive value of cognitive performance regarding job tenure was however less robust than the conclusion drawn in the first part of the study (in which the authors found that cognitive performance did not play a role in finding employment). The reason was that a minority of subjects worked significantly more hours than most of the 40 subjects that found employment. The

¹⁰ Aspects assessed were language/academic ability, general intellectual ability, attention, executive functioning, motor functioning, memory and neuropsychological status.

authors concluded that their study succeeded in alerting service providers to the need to test assumptions made about the impact of cognitive performance on people's ability to work (Gold et al., 2002).

Psychosis is another component that is often associated with high risk and an expectation of failure at work. This can be seen in the number of studies that investigated the prevalence and/or severity of psychosis experienced as a possible predictor of reduced ability at work. My own experience of work in rehabilitation settings and also, more recently, attempts to establish learnerships¹¹, gave me appreciation of the depth of misunderstanding and fear associated with psychosis in particular. One study (Racenstein, Harrow, Reed, Martin, Herbener and Penn, 2002:95) found psychosis to hamper work adjustment. It was specifically the duration of psychosis that was found to be affecting work. This was a 10 year longitudinal investigation to explore the association between positive symptoms of psychosis and instrumental work functioning amongst patients with schizophrenia, compared to patients with affective disorders. Participants (n=173) were assessed for the presence of psychosis and concurrent work adjustment at four consecutive follow-ups. A significant relationship ($p < 0.01$) was demonstrated between psychosis and increased impairment in work functioning across all diagnostic groups for three of the four follow-up periods. The authors concluded that the more severely psychotic patients, regardless of diagnosis, were least likely to be working effectively. However, the debilitating effect of psychosis on work adjustment was most evident for people with schizophrenia. The process of sampling used revealed a significant difference in the number of years of education completed between the diagnostic groups. Those with nonpsychotic depression had completed more education. After stratifying the entire sample for high versus low education, findings remained consistent in showing poorer

¹¹ Learnerships are particular training opportunities in natural work contexts that are made available under auspices of a Sector Education Training Authority (SETA). Disabled people are one of the designated groups that SETAs are expected to focus on.

work performance for participants who experienced psychosis. Effective functioning at work was defined as “working continuously more than half the time or full-time in the year prior to the follow-up” (Racenstein et al., 2002:99).

Research presented in this section has shown the danger inherent in expectations or assumptions that either the type of symptoms, or the severity of symptoms, could comfortably be used to predict the ability of people with psychiatric disability to participate in programmes or employment.

3.2. Functional and work skill level

Boardman, Grove, Perkins and Shepherd argued that mental health professionals underestimate the capacities and skills of their clients to return to work (Boardman et al., 2003a). They ascribed this tendency to a lack of appreciation of the importance of work and employment, the dominance of an illness model that emphasises symptoms and cure and neglect of the social aspects of management. Killeen and O'Day found low expectations to be imbedded in policies and programmes of participants in their qualitative study (Killeen and O'Day, 2004). Participants' stories were saturated with negative messages and low expectations; many of these the result of negative messages from vocational consultants or other rehabilitation professionals. Some participants were told directly that they would not work again, others were placed in unskilled low-wage positions and counselled to stay in it for a long time and advice was given to prioritise maintaining Social Security benefits (therefore restricting earnings by choosing low-pay work or working part-time). The illness-focus of programmes in which conversations were dominated by symptoms, medication, stress levels and daily habits whilst abilities and interests were unwittingly relegated to the background were found to be counter-productive (Killeen and O'Day, 2004). Rehabilitation professionals were often guilty of ignoring the possibility that stress created

by poverty-level lifestyle may be more of a threat for relapse than challenging work. An important finding was that each of the participants who were successful at maintaining employment had received positive messages about their future potential from other sources (Killeen and O'Day, 2004). Other factors that facilitated successful participation in work were access to education or training, a collaborative relationship with mental health professionals and peer and community support.

Functional skill level is often used to judge the ability of people to work. In South Africa, such assessments are usually¹² made with applications for a disability grant. Specialised work assessment units rely on functional assessments to supplement their assessment of performance deficits, when decisions are made about the ability to work. The underlying assumption is therefore that functional skill is a good indicator of ability to work.

Arns and Linney explored the relationship between the functional skills of clients with severe mental disorders and the benefits to the client and to society (Arns and Linney, 1995). Functional skills included communication and social interaction, personal care and hygiene, cooking, the use of transportation, ability to handle finances and to maintain a schedule. Benefits, in this study, were reflected by residential and vocational status, self-efficacy, self-esteem and life satisfaction. Initial correlations were followed up with multiple regression analysis, to explore the relationship between various outcome variables, demographic details, clinical characteristics and ratings of functional skills (rated by staff) of 139 people with severe mental illness (excluding substance abuse). The authors concluded that functional skills were highly and significantly related to level of independence in residential and vocational settings, but not to measures of intrapersonal benefits such as

¹² This depends on geographical area, and therefore resources. Assessments in areas without work assessment units are only medical.

self-esteem, self-efficacy and life satisfaction. Their overall conclusion was that skill level is generally a better predictor of the stated benefits than diagnostic or demographic variables (Arns and Linney, 1995).

A similar conclusion was reached in the study by Anthony et al. (1995) that was introduced earlier. The authors found ratings of work skills to have a positive correlation with vocational outcome.

3.3. Exposure to vocational programmes

A strong trend emerged, particularly in the last decade, of research that measured (and sometimes compared) the effectiveness or outcomes of various approaches with vocational goals. Particular emphasis has been given to supported employment as a programme option that replaced more traditional vocational rehabilitation approaches. A range of service models, each with variation in approach, were put forward as a possible solution through which employment can be supported and maintained; these included transitional employment, supported employment, individual placement and support, natural supports and sheltered workshops (Barker, 1994). Supported employment was defined as “competitive employment in an integrated setting with ongoing support services for individuals with the most severe disabilities” (Cook and Burke, 2002:548).

Blankertz and Robinson conducted a randomised control trial to examine the effect of adding a vocational focus to mental health rehabilitation (Blankertz and Robinson, 1996). They randomly assigned 122 clients to a programme with an employment specialist or to a control group with no specialised vocational service. The employment specialist did individual sessions (once a week) and group sessions (four times per week) and provided individual advocacy, as well as long-term support. Four stages, or sub goals, were identified in the ‘ladder of success’ towards achieving vocational participation.

At nine months, 34 of the 61 clients assigned to the vocational programme achieved positive changes in vocational status, including some clients that were involved in competitive employment. Only one client from the control group achieved positive changes in vocational status; this client was linked to the state vocational rehabilitation system. All participants assigned to the vocational programme showed skill gains and positive changes in work attitudes. The results showed that involvement in a programme with a vocational focus, rather than individual client characteristics, was an important predictor of positive outcome at work (Blankertz and Robinson, 1996). The results obtained in this study were strengthened because they were obtained in a prospective study to which participants were randomly allocated to either a service with a vocational focus or one without such a focus.

3.3.1. Reflections on traditional vocational rehabilitation

Rehabilitation professionals, including occupational therapists and social workers, have made important contributions in the development of programmes that focus on improving the work abilities of people with psychiatric disabilities. Vocational rehabilitation service models were developed with the goal of achieving sustained involvement in work. These programmes have however had limited success in the South African context. In the past, vocational rehabilitation service models were informed predominantly by the medical model. The underlying assumption was therefore that disabled people were rehabilitated away from natural work contexts, with the ultimate goal of them obtaining work, either in the open labour market or in sheltered or protective environments. The focus tended to be on problems rather than ability, without real consideration of personal interests or job preferences.

Some criticism of vocational rehabilitation service models was discussed by Rumrill Koch and Harris in an article that examined future directions for vocational rehabilitation in the United States (Rumrill, Koch and Harris, 1998). The authors acknowledged some changes that had already been made, but asked for more emphasis to be placed on consumer involvement; a focus on ability as opposed to inability; achievement of positive employment outcomes; and retained work (Rumrill et al., 1998). Some of the criticisms raised were mirrored by Strong in an ethnographic study to explore the meanings and situational constraints experienced by consumers of mental health services (Strong, 1998). She found that participants in her study experienced a personal sense of failure for "not having stayed well" which was reinforced by "repeated failures and rejections in a system that places expectations on the individual, rather than on the system or environment to change" (Strong, 1998:34).

Overwhelming research evidence, that will be presented next, showed supported employment to be more successful than traditional vocational rehabilitation in the achievement of work outcomes.

3.3.2. Supported employment

The supported employment concept, which originated in the United States, is based on the assumption that when the right type, and intensity, of support is provided people with the most severe disabilities can (and should be) integrated into the labour market (Hoekstra, Sanders, Van den Heuvel, Post and Groothoff, 2004:40). The purpose of supported employment programmes has been described as being "to promote self-sufficiency and a more integrated and improved quality of life by helping persons with disabilities pursue job opportunities in traditional work environments at equal pay to non-disabled persons" (Jones et al., 2001:53). Essential steps taken as part of supported employment comprise assessment, job finding, job analysis,

matching and job coaching (Hoekstra et al., 2004). Supported employment affords employment opportunities for disabled people who fulfil the requirements of the job and are paid accordingly. Employment specialists, often called 'job coaches', provide ongoing support. The nature of support offered is determined by the needs of the worker, or by the particular supported employment programme. Support could include;

- ◆ transportation
- ◆ training, for example, money handling, grooming, use of transportation, or the management of symptoms
- ◆ programme development, including developing person-centred instructional plans such as behavioural intervention programs
- ◆ job advocacy such as advocating for a participant at the job site with employers, co-workers and customers
- ◆ non-job advocacy, for example, advocating for a participant, but not related to work, with parents, landlords, case managers, therapists, school personnel, bank personnel, doctors, etc.
- ◆ evaluation such as analysing a person's employment potential by interviewing him or her, reviewing records, communicating with guardians or involved agencies, and observing the individual in real or simulated work settings (Jones et al., 2001).

Becker, Smith, Tanzman, Drake and Tremblay examined the aspects of the supported employment approach that were the most strongly correlated with better employment outcomes (Becker, Smith, Tanzman, Drake and Tremblay, 2001). They found the provision of community-based services and the use of employment specialists to be the strongest indicators of employment. Community employment implied that vocational rehabilitation was provided in community settings away from the mental health centre. Reasons given for this were, firstly, that it reduced the need for a transfer of skills from one setting to another, secondly, it improved identification of clients' interests, strengths and natural supports and lastly, better relationships were established with employers directly. Another interesting programme

component, identified to have strong or moderate correlations with success in competitive employment, was a zero-exclusion policy. This meant that individuals were not screened for work readiness; everyone was encouraged to consider work opportunities and was supported in these efforts (Becker et al., 2001).

Supported employment is a relatively new model that is utilised to facilitate the employment of people with psychiatric disability. Evidence for the use of supported employment as a preferred model is increasingly found in the literature. Research, undertaken to assess its effectiveness, underscores the use of the model. For example, in a randomised control trial (RCT) (Lehman et al., 2002) the Individual Placement and Support (IPS) model was compared with more traditional models (some of which included a vocational focus) to compare their effectiveness at achieving competitive employment. Competitive employment was defined as a job in which (a) the worker earned at least the minimum wage, (b) the worker did not have contact with disabled workers and (c) the job had not been set aside for a disabled person. Patients (n=219) were randomly assigned to the IPS programme, or a traditional rehabilitation programme in which patients had a choice to participate in a group with a vocational focus. Nearly half (42%) of patients who were randomly assigned to the IPS model of intervention achieved employment compared to only 11% of the patients in the control group. Job retention figures in the IPS programme were however problematic, they levelled off in the range between 15% and 20%; much the same as the job retention percentage of those in the control group that found employment (Lehman et al., 2002). The researchers' decision to compare the IPS model with traditional rehabilitation programmes, when not all of these had a vocational focus, detracted from the findings obtained. Rehabilitation is a broad concept that may, or may not, have competitive employment as one of its outcomes. A comparison with exclusively vocationally focussed rehabilitation programmes would have been more beneficial. The study nonetheless

revealed that the IPS model was indeed a successful strategy in the achievement of competitive employment.

Similar results were obtained in another RCT in which subjects (n=143) presenting with severe mental disorders were randomly assigned to one of two programmes (Mueser, Becker, Torrey, Xie, Bond, Drake and Dain, 1997). The first programme, that offered integrated supported employment with individual placement and support, yielded significantly better rates of job attainment than the second programme that provided training in prevocational skills (related to selecting, finding and keeping a job). Nonvocational domains of functioning: symptoms, substance abuse, hospitalisations, self-esteem and quality of life were compared between the two groups (Mueser et al., 1997).

The Programme for Assertive Community Treatment is a service model that has many of the same characteristics of supported employment. The first similarity is that clients are trained in the course of work, rather than in anticipation of work. The second is that employment services are not brokered out to employment services. Instead, these are done by the team who take responsibility for employment. It was reported that this approach achieved vocational outcomes that were comparable with supported employment results; 60,8% of clients were employed at any given time during the research period (Becker, Meisler, Stormer and Brondino, 1999).

A systematic review by Crowther, which included eleven trials further supported the consistent evidence that supported employment was an effective strategy through which competitive employment could be achieved (Crowther, Marshall, Bond and Huxley, 2001). In this trial supported employment was compared with more traditional prevocational training. The conclusion was drawn that subjects in supported employment were more likely to be in competitive employment than those who received prevocational

training. Furthermore they earned more and worked more hours per month than those who had had prevocational training (Crowther et al., 2001).

Strong utilised an ethnographic design to explore what made work meaningful for people with persistent mental illness and explained how this meaningfulness related to their recovery (Strong, 1998). People (n=12) who had been involved with a formal mental health system participated in in-depth interviews and a focus group. Participant observation of 35 workers was also done in the context of an affirmative business. The meaning of work varied with participants' perception of their illness and their self-concept. Positive changes in their self-efficacy and self-concept were documented and linked to the experience challenges and successes in the context of meaningful work (Strong, 1998).

These studies clearly demonstrated the success that could be achieved by people with psychiatric disability, when they received appropriate support. Importantly, these programmes were situated in natural work contexts. While very few such programmes are currently available in South Africa, they are in line with visions for future development and strongly supported by new legislation.

3.3.3. Accommodation within regular work environments

The Code of Good Practice (Department of Labour, 2001) was developed to guide the implementation of the Employment Equity Act¹³. It details requirements placed on employers to maximise the contribution of disabled people through reasonable accommodation. Accommodation of psychiatric impairment is usually relatively inexpensive and could be very effective. Some examples include:

¹³ It contains principles and guidelines pertaining to reasonable accommodation in the workplace.

- ◆ Adjustment of work time and leave, including sick leave.
- ◆ Providing specialised supervision, training and support.
- ◆ Educating co-workers about psychiatric disability.

These developments are in line with the social model of disability. The focus is on making natural work environments accessible to people with psychiatric disabilities rather than rehabilitation that happens away from work in hospital contexts.

3.3.4. Consumer-run business, affirmative business, and micro-enterprise

The Integrated National Disability Strategy (INDS) highlighted unemployment as a fundamental problem affecting the majority of people with disability, and their families (Office of the Deputy President T. M. Mbeki, 1997). The creation of work opportunities for people with disabilities through the development and maintenance of small, medium and micro-enterprises has been proposed as a key component in a comprehensive employment strategy for people with disabilities. Developing a micro-enterprise is an exciting option to be considered by people with disabilities, who find themselves without employment. Succeeding in self-employment is however not a viable option for everyone. Development requires start-up funding, specialised knowledge, e.g. market research, pricing, marketing, etc. These require specifically focused training.

Consumer-run business is a relatively new idea to promote the participation of people with psychiatric disabilities in real work settings. Krupa (1998) described the concept of consumer-run business in depth. He proposed that the following characteristics need to be considered by a consumer-run business in assessing its viability:

- ◆ the extent to which the business is economically viable;

- ◆ whether or not the business is owned and operated by people with psychiatric disabilities;
- ◆ the extent to which it empowers individuals and members of the community.

Affirmative businesses are also operated by people with psychiatric disability, as in the case of consumer-run businesses, thereby giving people with psychiatric disability increased personal control. An affirmative business could be a form of flexible employment with a regular income in a realistic work environment (Strong, 1998).

The difference between a consumer-run business and an affirmative business is ownership. Affirmative businesses are not always owned by the people who operate them. The difference in expectations associated with starting a successful micro-enterprise, and entering an affirmative business, lies in the support and the structure provided. Affirmative businesses are usually made available in partnership with socially conscious business ventures, hospital staff who value the empowerment of people with psychiatric disability, or consumer action groups in the community. As such, they usually offer an existing structure and good support to the person with psychiatric disability wishing to join them.

3.3.5. Clubhouse model

The Clubhouse model developed from Fountain House, a club for men and women with mental illness, that dates back to 1943 (Fountain House New York City, 1999). The belief that work has a profound meaning in one's life is inherent in the Clubhouse Model (Di Masso, Avi-Itzhak and Obler, 2001). A further belief was that work has the ability to give people a sense of who they are, and 'pushes' them to discover their personal strengths and talents; further leading to development of self esteem. People with psychiatric

disabilities who accept membership are clubhouse members, rather than patients, consumers or clients (Fountain House New York City, 1999).

Most Clubhouses have temporary employment (TE) programmes available to members of the Clubhouse. TE programmes offer temporary work opportunities in competitive employment situations. TE programmes usually comprise 12-week job opportunities that club members rotate through in order to gain experience and build confidence. Criticisms have included;

- ◆ the lack of rigorous research to examine the effectiveness of TE,
- ◆ it does not offer direct, rapid movement into competitive employment,
- ◆ members might be less invested in temporary jobs and
- ◆ jobs are 'owned' by the clubhouse and not the member.

Henry, Barreira, Banks, Brown and Mckay set out to describe the experiences of members and identify both the predictors of tenure and the extent to which TE participation predicted competitive employment (Henry, Barreira, Banks, Brown and Mckay, 2001). Participants (n=138) who held TE jobs during a 6-year period were grouped into four types (1) maintenance, (2) production, (3) clerical and (4) customer services. Analysis was done to show significant differences in job type. Obtaining competitive employment in the year following TE was positively correlated with average number of days worked per week within the TE. Cumulative hours worked on TE showed the strongest relationship to the one-year employment outcome; members who worked more TE jobs and had longer tenure cumulated more hours and were more likely to obtain competitive employment (Henry et al., 2001).

One such programme that offers a broad range of educational and work opportunities was the Menu Approach that operated on the following principles (Chandler, Levin and Barry, 1999) (1) a belief that work offers many benefits besides a means to "pay the bills"; (2) virtually all consumers can participate in and benefit from meaningful paid work; (3) consumers should be able to choose from a "menu" of employment options; and (4) multiple trials of different kinds of paid work are an important part of

developing long term employment in competitive settings. Other supported employment programmes operate on similar principles, thereby creating empowering environments for people with psychiatric disability to participate in work alongside their non-disabled counterparts.

3.4. Duration and the nature of support

People with psychiatric disability who are working successfully (including some of the participants in the present study) often did not maintain work when they first attempted it. For many it took repeated attempts for them to obtain work. I believe that service providers have to be willing to keep their minds on employment as something that might be a long-term goal.

Arns and Linney positively and significantly related length of programme membership to vocational status in their study that was introduced earlier (Arns and Linney, 1995). The authors speculated about the supportive role psychosocial rehabilitation programmes could play in assisting people with severe mental illness to remain productive (Arns and Linney, 1995). Another study cited earlier (Anthony et al., 1995) found that clients who remained in the psychosocial programme for at least one year experienced a reduction in symptoms, particularly negative symptoms, as well as improvements in work skills. These studies demonstrated that a short-term bias might impede the success with which people with psychiatric disability are able to integrate into work context when such opportunities arise.

In the cited study by Jones, Perkins and Born it was concluded that clinical and demographic variables did not significantly predict work outcome, or the amount of supported employment services used (Jones et al., 2001). Their second, very important, conclusion was that the specific quantities and qualities of supported employment services received prior to working distinguished those who later worked from those who did not work. This

important finding was discussed by the authors (sic) to show how broad scope support assisted with the anticipated training needs of participants within work settings. The authors emphasised the need for the type of additional support that employment specialists provided in non-job settings.

Salyers, Becker, Drake, Torrey and Wyzik conducted a ten-year follow-up of clients (n=36) who were originally studied when two separate day treatment programmes were converted to supported employment programmes in the early 1990s (Salyers, Becker, Drake, Torrey and Wyzik, 2004). One of their hypotheses was that clients who had participated in the original supported employment programme would obtain jobs over the ten-year period that would be characterized by longer job tenure and high satisfaction. A semi-structured interview was used to gather information about demographic characteristics and facilitators of employment. Potential facilitators of employment were also rated, using structures that were developed for this purpose. Two factors, namely reduced work hours per day or days per week and knowledge about disability benefits were cited most frequently by participants who worked. The authors emphasised the benefit of a long-term perspective when working with clients within a supported employment programme (Salyers et al., 2004).

3.5. Other variables considered to be predictive of work

Self-esteem

Self-esteem is another dimension that is often expected to impact on the choices people make and on their behaviour in general. Research that dealt with issues of self-esteem was discussed earlier in this chapter. The impact of stigmatisation on self-esteem has been considered (Link, 1982; Link et al., 1989), as well as the consistency with which self-esteem and self-efficacy predict success at work (Link et al., 2001). Many authors concerned

themselves with issues around self-esteem; self esteem was often used to measure outcomes of rehabilitation programmes that might, or might not, have had a vocational focus (Arns and Linney, 1995; Mueser et al., 1997). It is thus often used to measure outcome, rather than being investigated as a variable that might impact on employment outcome.

One study, in which particular emphasis was placed on self-esteem alone, found an inconsistent relationship between work status and self-esteem (Torrey, Mueser, McHugo and Drake, 2000). A secondary analysis was done to look more specifically at self-esteem as an outcome measure in studies of vocational rehabilitation. Work status and work experience were measured to investigate the relationship between self-esteem and work. Findings revealed that participants who were competitively employed had lower scores on the Rosenberg Self-Esteem Scale (implying a better self-esteem) at each follow-up assessment point. These scores were however not statistically significant. Work history was explored by placing participants into categories of no work, low amount of work and high amount of work according to the number of weeks they worked in paid, competitive jobs. While no significant difference over time was measured for the 'no work' and 'low amount of work' groups, the self-esteem of the 'high amount of work' group had improved (Torrey et al., 2000).

Work history

The literature reviews conducted by Anthony were introduced in 3.3.2. He concluded that employment history emerged as the one demographic variable that was most predictive of future vocational success (Anthony, 1994). A similar conclusion was reached by Moller, Von Zerksen, Werner-Eilert and Wuschner-Stockheim who conducted a five-year follow-up study (using standardized instruments) to determine what types of outcome indicators were best to use to predict work participation (Moller, Von Zerksen, Werner-Eilert and Wuschner-Stockheim, 1982). Their sample consisted of patients

with schizophrenic or paranoid psychoses. They found the duration of occupational disintegration and psychiatric hospitalisation to be the strongest predictors of social adjustment at follow-up (Moller et al., 1982). Arns and Linney also found a positive relationship between the history of competitive employment and vocational status in their study (previously discussed) (Arns and Linney, 1995).

The positive relationship that was demonstrated between work history and participation in work might have been expected, because, having a work history implies in itself an ability to work. Also, it has been shown that work can ameliorate health and wellness (Mogulowsky and Rumrill, 1996; Polak and Warner, 1996; Lehman et al., 2002; Boardman, Grove, Perkins and Shepherd, 2003b). One might therefore make a deduction that participation in work itself, because of its ability to enhance wellness, could over time enhance the ability to work.

Job preference and interest

Becker, Drake, Earabaugh and Bond were concerned that mental health practitioners often consider people with mental illness to have unreal work expectations and underdeveloped vocational goals (Becker, Drake, Earabaugh and Bond, 1996). They launched a study in which they coded clients' job preferences retrospectively (after their job search was complete) in order to answer four questions:

- ◆ Do people with severe mental illness, who enter supported employment programmes, have job preferences?
- ◆ Are their preferences stable over time?
- ◆ Do clients, who obtain jobs in their preferred areas, have greater satisfaction and longer tenure than people who obtain jobs in non-preferred areas?
- ◆ How do clients develop job preferences?

Clients were considered to have a job preference when 80% of the job search contacts were in a particular vocational area. Similarly, clients were classified as "undecided" if less than 80% of job search contacts were in any vocational area. Findings showed that psychiatric clients were neither naïve, nor unrealistic about job choices. Participants who signed up for the supported employment programme had explicit job preferences; they did not need extensive counselling or skills training to develop realistic job choices. Clients' job preferences remained relatively stable over time and clients in this study who obtained employment in keeping with their preferences had greater satisfaction and longer tenure than people who obtained jobs in areas outside their preferred area (Becker et al., 1996). Killeen and O'Day's (Killeen and O'Day, 2004) findings did not only show that participants' own interest and preferences are important, but also illustrated clearly that people with psychiatric disabilities should participate in decision-making. Their findings highlighted the motivational spin-offs experienced by people with psychiatric disability when a collaborative relationship was set up with rehabilitation professionals who gave consideration to their views and opinions.

Careful consideration of needs, abilities and preferences is required to achieve the successful placement of people with psychiatric disabilities in work. Kravetz, Dellario, Granger, Salzer proposed a multifaceted work participation approach in which the environment is also well thought-out (Kravetz, Dellario, Granger and Salzer, 2003). According to this approach different sets of intra-personal and inter-personal resources and processes help people to participate fully in the work life domain. The two-faceted approach considers the 'person' within a 'work environment' that is in turn impacted on by 'service/support systems' and 'cultural/socioeconomic factors' and proposes a holistic view in order to facilitate competence in work as well as career development.

Incentives

A study that was conducted in the United States examined the relationship between compensation payments and employment amongst war veterans with psychiatric disorders and war veterans whose impairments were non-psychiatric (Rosenheck, Frisman and Sindelar, 1995). They found that veterans with psychiatric disorders who received compensation of less than \$500 per month were no less likely to work than those who did not receive any compensation. Overall a modestly significant relationship was found – for each additional \$100 per month received in compensation, a 2% decline was found in the veterans who worked. There was also a decline of 1 hour per week in hours worked and a reduction of \$1 100 per year total income. However, veterans with psychiatric disorders whose compensation was \$500 or more (average was \$1004) worked and earned significantly less than other groups. It is important to note that no significant difference was found between veterans with psychiatric impairments and those with non-psychiatric impairments in the relationship between disability payments and employment (Rosenheck et al., 1995). The problems associated with underemployment of people with psychiatric disability in low-performance jobs are increasingly being explored in the literature (Blankertz and Robinson, 1996; Cook and Jonikas, 2002; Killeen and O'Day, 2004; Chandler et al., 1999). More emphasis should be placed on meeting the needs and preferences of people with psychiatric disabilities when they are placed in work.

South African research to explore possible relationships between disability benefits and participation in work has not been done. Although research to explore possible relationships between disability benefits and participation in work has not been available in South Africa, the issue is often raised in political debates. Arguments are contradictory and elusive. Some people view disability payments as a stunting of incentive for disabled people to seek employment, because it is argued, motivation is reduced. Another aspect under consideration is that disabled people might not work for risk of losing

the benefits when work is obtained but not maintained. Disabled people who rely on their disability payment as the only source of income will often not risk a discontinuation of the benefits in order to find work. This is a concern that is often raised by disabled people themselves.

The effect of medication

Limitations in the efficacy of medication, or its correct prescription and administration is an influence that will be recognised by all who have worked in mental health settings. Effective medication, and compliance with the use of such medication has a direct impact on the illness experience. Research in which medication is considered is focussed on the effectiveness with which each type of medication alleviated symptomatology; very few studies have been undertaken to investigate the impact of medication on work. Meyer, Bond, Tunis and McCoy (Meyer, Bond, Tunis and McCoy, 2002) set out to determine whether new medication, shown to have improved efficacy, correlated with better employment outcomes than more traditional medication. They utilised a naturalistic cross-sectional design to investigate whether improved new generation medication led to better outcomes at work. The findings did not show a significant difference between the two different treatment groups (Meyer et al., 2002).

Environment

Kirsh explored the impact of environmental as well as individual variables on the work of mental health consumers (Kirsh, 2000). The relationship of four variables to employment, namely empowerment, social support, organizational culture/climate and person/environment fit were considered. Consumers (N=36) were recruited from one of two groups; (1) consumers who were employed in integrated settings (n=17) and (2) consumers who had recently left their jobs (n=19). The two groups were found to be highly similar in demographics. Data were gathered using the Empowerment

Questionnaire; the Interpersonal Support Evaluation List, the Workplace Climate Questionnaire, and the Organizational Culture Profile. Data analysis revealed significant group differences along the dimensions of organisational climate and person/environment fit. The results pointed to the importance of considering workplace climate and its congruence with individuals' value systems in promoting positive vocational outcomes.

Cook and Burke considered the future of psychiatric rehabilitation within the New Paradigm¹⁴ (Cook and Burke, 2002); they believed that a shift in focus away from being solely on the individual to one that equally encompasses the environment would be required. Such a focus would also consider environments that are often socially inaccessible, economically constraining, legally exclusionary, and emotionally unsupportive because of high rates of poverty and a lack of self-determination (Cook and Jonikas, 2002). They also believed that the source of interventions should be expanded beyond health professionals and clinical/rehabilitation service providers to include peers, mainstream providers, and consumer advocacy and information services (Cook and Jonikas, 2002).

“Most importantly, in the New Paradigm the role of the person with a disability shifts from being an object of intervention or a patient to one of a customer, empowered peer, and decision-maker” (Cook and Burke, 2002:543).

Conclusion

The literature review presented conflicting findings, opinions and unanswered questions; something one might expect when considering the complexity of

¹⁴ The authors understood a new appreciation of disability rights and subsequent development of legislation to have set the scene for a new paradigm in which disabled people will enjoy more equality and inclusion.

the issues under review. However, the absence of research that communicated the perceptions, experiences or views of people with psychiatric disabilities themselves was unexpected. The positivist paradigm, that so clearly dominates research activities in this field, necessarily stripped away contextual detail and individual characteristics, in order to measure or compare characteristics or elements that were considered to be of clinical importance. The result is a silencing of the voices of people with psychiatric disabilities and the tendency to lose those stories that do not closely resemble the pattern considered to be the norm.

It became clear that research was needed that:

- ◆ did not fracture human beings from their experiences, dreams or their unique understandings of the influences that shaped their participation in the world of work,
- ◆ captured the impact of context on the behaviour, choices and experience within natural environments and
- ◆ accepted stories of lives that fall outside the 'norm' as valid and important even though these do not mirror the majority.

It was with these thoughts in mind that I undertook this study, which sought to examine the work and work-related experiences of people with psychiatric disability.

Chapter 4: METHODOLOGY

Introduction

This chapter begins by exploring concerns around legitimation and the establishment of truth because these issues were prominent in discussions during the initial stages of the study. Reasons for the primacy of these concerns relates to

- (1) my own work context that is dominated by positivist traditions,
- (2) my reading of post-structuralism and post-modernism, and
- (3) assumptions made about people with psychiatric impairment, particularly that they might not be able to participate in the construction of answers to the research question. These matters will now be briefly discussed below.

1. The Faculty of Health Sciences at the University of Cape Town, has a proud research history that has been firmly grounded in positivist traditions. Research that relies on qualitative research methodologies has become a regular occurrence and is gaining acceptance. However, most prominent researchers remain sceptical of the contribution that could be made when approaches used fall outside the positivist paradigm. Explanations are often required to defend a methodology that accepts the existence of multiple realities and that relies on subjective and intersubjective knowing, as opposed to objective knowing. Interactive or participative methodologies are often mistrusted because of positivist assumptions that the investigator and object being investigated should remain separate, in order to avoid bias. Researchers who use qualitative methodologies in this setting do so with strict adherence to postpositivist strategies in order to represent the authentic voices of participants, with very little interpretation of the content. My broad exploration and discussion of

the dilemmas that are faced by qualitative researchers should be read against this background.

2. Whilst I am comfortable with these methodological issues, my own positioning within post-structuralist or post-modernist arguments has been more ambiguous. In particular, those interpretations pertaining to the credibility of qualitative research and the establishment of truth. I therefore explore these issues in some detail.
3. A concern, that people with psychiatric disability would not be able to participate in the construction of answers to the research question, was raised several times in the early stages (protocol development) of the research. I will therefore explore this concern here, even though it is one I do not share. Three main points formed the basis for concerns raised; (a) that participants might 'lack insight', (b) that participants might be experiencing relapse, which might include psychosis and (c) that participants might be 'defended', therefore trying to paint a picture that would not show the real reasons for them not working.

The concerns I had, were related to ensuring that the conclusions reached at the end of the research process would be trusted as credible, and that it would meet quality standards. A further task was to clarify, for myself and for the reader, what was meant by 'truth'. These issues will be explored in Section A.

Section B will provide a rationale for choosing interpretative biography together with narrative interviews in a research partnership through which data was constructed. This section will furthermore situate the methods of analysis that were used.

In Section C a detailed description will be given to show how the methodology was applied in action.

Section A: Notions of truth

4A.1. Responses to crises of legitimation and representation

Denzin argued for “a triple crisis of representation, legitimation, and praxis” (Denzin, 1997:3) which qualitative researchers in the human disciplines face (*sic*). Several authors are cited to support his conclusion that two key assumptions of qualitative research have become problematic within the discourses of post-structuralism and post-modernism. The first assumption carries a representational crisis and “presumes that qualitative researchers can no longer directly capture lived experience” (1997:3). Instead, such experience is created “in the social text written by the researcher” (1997:3). The second assumption holds a legitimation crisis because it “makes problematic the traditional criteria for evaluating and interpreting qualitative research” (1997:3). I will focus on the legitimation crisis first, for reasons given in the introduction to this chapter. I will then briefly touch on the representation crisis to show how it shaped my understanding of the nature of truth. In their introduction Alvesson and Skoldberg drew a distinction between “the great mainstream of empirically orientated research” (Alvesson and Skoldberg, 2000:1) and various currents that are critical of empiricism on diverse philosophical or theoretical grounds. They drew a parallel between this division and the dichotomy between scholars who adopt a robust and objectivist ontological approach and those with a consciousness and experience oriented, interpretive view of ontology and epistemology.

4A.2 Locating processes of legitimation and credibility

Readings I undertook to inform me of the art and science of doing qualitative research, pointed me to the use of four criteria, namely *credibility*, *transferability*, *dependability* and *confirmability* to judge trustworthiness of

qualitative research findings (Lincoln and Guba, 1985). These criteria were put forward for use instead of criteria such as *validity* and *reliability* that are the hallmarks of the positivist tradition. Several strategies, including *member checks*, *prolonged engagement*, *audit trail* and *peer debriefing* were developed for use to make sure each of the four criteria was adequately fulfilled (Krefting, 1991). When I read more of Denzin's work, in preparation for the present study, I came to understand that his views were in fact different. Considering that I was utilising Interpretive Biography, as described by Denzin, I believed it would be wise to explore Denzin's views in order to ensure coherence.

Denzin presented four responses to the legitimation crisis that are faced by qualitative researchers; these are summarised below (Denzin, 1997):

Positivists operate on the belief that a single set of criteria should be applied to all scientific research. Qualitative and quantitative research should use the same four standard criteria namely internal validity, external validity, reliability and objectivity. The paradigm is organised around a normative epistemology, which contends that "normal is what is most representative in a larger population, and it is to that 'normal' population that generalizations are directed" (Denzin 1997:7).

Post-positivists argue that qualitative research should use a different set of criteria. Agreement on the particular criteria that should be used has not been reached, but all agree that criteria should be different from those of quantitative research.

Post-modernists believe that ethnographic practices are seen to be ways of acting in the world. These produce particular, situated understandings; the validity or authority of which is determined by the critical understandings produced (Denzin 1997). Attention is given to the deconstruction of concepts in order to counteract attempts at proposals that a 'real' world exists around which lasting theories can be developed.

Critical-Poststructuralist argue that "an entirely new set of criteria, divorced from the positivist and post positivist traditions, need to be constructed. Such

criteria would flow from the qualitative project, stressing subjectivity, emotionality, feeling and other antifoundational criteria" (Denzin 1997:9).

Denzin proposed alternative ways of looking at truth within the post-modern world (Denzin, 1997). These do not come in the form of easily definable strategies; instead they represent criteria that could be used in a process of deconstruction that is situated in Critical Post-structuralism. Attention is given to *politics*, and to the contradictions brought to mind by *verisimilitude*. These two constructs were incorporated in the present study in ways that will now be explained.

4A.3. Explicating politics and values as elements of good research

Denzin explained the measure of a good text as being situated in the extent to which it "seeks to understand how power and ideology operate through systems of discourse, asking always how words and texts and their meanings play a pivotal part" (Denzin 1997:10). It follows that the extent to which a researcher succeeds to situate texts within the broader social and political context would determine the credibility and quality of the study. Moreover, knowledge is socially constructed. The consequence is that questions asked, responses given and understanding of such responses would be influenced by the social and political situatedness of researchers and participants. Such foundations are frequently not a conscious mechanism of interaction, instead they operate as a tacit undertone of the opinions that are shared and understood. Denzin argued that texts should be taken on their own terms since it is not possible to produce a valid and authoritative text; therefore values should guide and govern science (Denzin 1997:9). Mays and Pope agreed, believing that all research was selective, and that the researcher could not capture the literal truth of events in any sense (Mays and Pope, 1995). Instead they believed it depended on collecting particular sorts of

evidence through the prism of particular methods, each of which had its strengths and weaknesses (Mays and Pope, 1995).

As a South African who grew up in the *apartheid* era, and is now experiencing the transition of our society, I appreciate how the powerful influence of politics penetrate personal domains, such as religion and relationships. It is unnecessary to make a case for the prominence of politics as a social determinant that shapes almost every dimension of people's lives. The issue that should be raised is how seldom such influences are recognised as a pertinent factor in research. The research reviewed and presented in the previous chapter did not take into account the political and/or social forces that might have influenced the questions asked and the answers constructed. For most studies, no attempt was made to explore why people with psychiatric disability have remained on the margins of society and, in fact, the disability movement. The tendency to limit the focus of research by excluding issues situated in the macro context might be a characteristic of health research. The absence of political will, required to bring about change, is ignored. Instead, reasons for non-participation are sought at a micro level, for example symptomatology, or at a meso level, for example the type of intervention used.

An explanation for this lethargy has to be tied in with the dominant values that are held on the subject of integration of people with psychiatric disability. People with psychiatric disability stand to benefit from the political impetus for the integration of disabled people into mainstream society. However, questions have to be raised about the reasons for the selective neglect of the cause of people with psychiatric disability in particular. My intention in the previous chapters was to explore potential political drivers that might benefit people with disability as a group. A further attempt was made to show that people in South Africa with psychiatric disability are being overlooked and their needs neglected. In the next chapter a sensitising of the values that underpin the (mostly) attitudinal barriers that prevent full integration of

psychiatrically disabled people will be carried out by exploring stereotypes. This is done with an assumption that tacit values held in mainstream society are present in the form of stereotypes.

During the study I came to appreciate how intensely the social interpretations, made by participants themselves and those who were close to them, influenced their thoughts and shaped their behaviour. The wisdom of Denzin's standpoint, which suggested that the legitimation of research texts lay in the exploration of political intentions that were at play (Denzin, 1997), was confirmed. These influences were predominantly situated in the macro and meso environments. It should be noted that social policy always takes time before it is implemented. A further time period should be allowed before such change can be expected to infiltrate public thinking. Allowances have to be made for a 'catch-up' period between each of these stages.

4A.4. Situating the use of deconstructive verisimilitude and credibility

My efforts to construct legitimate and credible answers to the research question rested on *member checks* and *prolonged engagement*. Krefting proposed the use of both these strategies (Krefting, 1991) for use to achieve *credibility*. However, the limitations of these strategies were shown in Denzin's criticism of a reliance on verisimilitude as a mechanism used to establish truth:

"The truth of a text cannot be established by its verisimilitude. Verisimilitude can always be challenged. Hence a text can be believed to be true while lacking verisimilitude. (The opposite case holds as well.) Challenges to verisimilitude in qualitative research rest on the observation that a text is always a site of political struggle over what is real and its meanings. Truth is political, and verisimilitude is textual.

The meaning of each of these terms is not in the text but rather brought to it by the reader” (Denzin 1997:12).

The limitation of truth as it is told, based on experiences, has been the topic of much discussion and reflection in social science. The reasons for this are usually not associated with something as simple as a research participant not telling the truth. Instead the production of knowledge is complicated by a number of factors:

The analogy of a murder mystery novel helped to illustrate Denzin’s concerns with the use of verisimilitude as a standard of truth. He explained that what seems to be true in such novels is usually shown to be untrue, while what seems untrue, is often found to be true (Denzin, 1989). He concluded a detailed discussion that explored the presence and absence of verisimilitude and truth in texts as an indicator of validity or legitimation, with the following statement:

“A text’s verisimilitude is given in its ability to reproduce and deconstruct the reproductions and simulations that structure the real” (Denzin 1997:13).

In their discussion Alvesson & Sköldberg concluded that the critics of empiricism held the view that “culture, language, selective perception, subjective forms of cognition, social conventions, politics, ideology, power and narration all, in a complicated way, permeate scientific activity” (Alvesson & Sköldberg 2000:2). They believed that “the relation between reality and text (the research results) is at best uncertain and at worst arbitrary or even non-existent” (Alvesson & Sköldberg 2000:2).

In previous research experiences my focus had been on establishing credibility. This informed my decision to once again rely on member checks as a starting point for the establishment of truth. However, my reading of Denzin’s concerns led to my doing them differently. Rather than merely

confirming understandings of interviews that preceded the member check, a framework of categories (which was the outcome of early analysis processes) was discussed with the participants. Questions that had come to mind since the interview were discussed with the participant; often such questions highlighted what looked to me to be contradictions. The process allowed participants to 'revisit' their own shared experiences, often adding depth or specificity. It also allowed them to 'rethink' their own constructions in the light of an emerging framework that included the views of other participants. Verification was not done by asking participants to 'check' interpretations and 'approve' correctness. Instead, discussion was re-entered and participants would further elaborate or clarify their responses. Thalitha¹⁵ for example questioned an early theme that emerged that I had named 'Notions of a spoiled identity'. She shared her view that having bipolar mood disorder was part of who she was and that she could not remember a time in which she was different. She explained that being Thalitha meant having those characteristics that she ascribed to having a bipolar mood disorder. She also pointed out that the word 'spoiled' implied lasting damage, something Thalitha (and a few other participants) disagreed with because they identified positive spin-offs that resulted from having a psychiatric impairment. Thalitha's views led to modifications of her conceptual framework, but more importantly, to a new understanding of the interrelatedness of her identity and impairment.

Prolonged engagement meant that a third interview was conducted at least three months after the first interview. For most participants the interviews stretched over a period of at least one year. This allowed for a relationship to develop and patterns to emerge that went a long way to improve the quality of data that was produced. One example was Jessica who had a 'broken' work history, with a dominant pattern of terminating work after three months. She

¹⁵ All names used are pseudonyms. Thalitha was a participant in the study, who will be introduced in chapter 5.

told me that she was in fact a very good worker and that she would be welcomed back at any of her previous places of work. During our first interview I understood this to be a contradiction that remained at the forefront of my mind. This view was altered slightly when, at the time of our second interview (six months later), Jessica was working as a locum in the salon from which she had resigned two weeks earlier (at almost double her original salary). During our third interview Jessica, who had been working for one year in the same salon, was thinking of leaving. She was happy with her development and her improved ability to maintain one job, but thought it was time to 'move on'. Jessica's employer must have been satisfied with her performance because she had recently identified Jessica as "the best investment she had ever made". Jessica arrived for our fourth interview having come directly from a breakfast meeting that she had with the same employer, even though she had resigned from her job about two months earlier. She described that meeting as a good one and told me that it was a good decision to 'stay in touch'. The complexity of influences that impacted on Jessica's decisions about work would have been lost if I had conducted a single interview. In fact, the contradiction that was so evident in the first interview would have led to an oversimplification of Jessica's ability as a worker; judgements made would have been superficial and unjust.

Member checking was therefore used as a vehicle through which a provisional analysis framework was jointly scrutinised and discussed in more depth. Through this process some verification, as well as deconstruction, was done. The outcomes of these strategies were provisional; they provided a rich foundation for further interpretation. Prolonged engagement added to the quality of findings in that behaviour patterns and the nature of relationships formed added to the understandings that were gained during interviews. Care was taken to further scrutinise occasions of verisimilitude and of contradiction in order to steer clear of oversimplification of influences at play in the lives of participants. Whilst the truthfulness of participants was never in question, I did not expect them to have 'ready-made' answers to the research questions.

In the construction of answers to the research questions serious attention was given to ensure trustworthiness at every step of the process, however, without an expectation that a stable truth or a single truth would be the outcome of the research.

4A.5. Locating issues of representation

Differences about the issue of representation seem to be one of the strong points of disagreement between qualitative researchers who hold different perspectives. This is not surprising, because to debate the issue of representation would usually draw into question the very processes with which the voices of participants are believed to be captured and presented. I myself consider that such opinions are, in turn, strongly influenced by views that are held about the nature of truth. Denzin's view of the representational crisis is characterised by the assumption that "much, if not all, qualitative and ethnographic writing is a narrative production..." (Denzin 1997:4). He explained that the writing of narratives poses particular complexities because of the presence of four paired terms in any social text. These are (a) "the 'real' and its representation in the text, (b) the text and the author, (c) lived experience and its textual representations, and (d) the subject and his or her intentional meanings" (Denzin 1997:5). The assumption that follows is that "there is a world out there (the real) that can be captured by a 'knowing' author through the careful transcription (and analysis) of field materials (interviews, notes, etc.)" (Denzin 1997:4). Denzin, positioned within critical post-structuralism, challenged these assumptions by stating that:

"Language and speech do not mirror experience: They create experience and in the process of creation constantly transform and defer that which is being described. The meanings of a subject's statements are, therefore, always in motion." (Denzin 1997:5).

Examples of this were experienced in the present research. Nicolas understood that his friends no longer wanted him to be a member of the

snooker club when it was discovered, after discharge from hospital, that he was no longer included in the A team. He thus withdrew from the one meaningful social context with friends. A further implication was that he no longer participated in a leisure occupation that brought him much fulfilment and joy (Nicolas was playing snooker on a daily basis). Other social contexts were made uncomfortable by the fact that Nicolas, unlike his friends, did not use any alcohol. During our second interview this issue was further explored with Nicolas trying to identify the motivations his friends might have had to exclude him. During this discussion, Nicolas changed his mind about the fact that he had been excluded, and wondered whether perhaps his friends were being 'over-protective' when they moved him from the A team to the B team. He went away from the interview without mentioning his intention to discuss this with his friends, but returned to the third interview weeks later to report that he had been re-instated in the A team and that he was happy to be involved with the club and his friends again.

Denzin gave three complex reasons in his explanation of the crisis of representation. Short summaries will be given here, before the implications for the present study are discussed.

4A.5.1. Lived textuality rather than lived experience

Denzin argued that lived experience is transformed by lived textuality. The basis for this argument is found in his view that the direct link between experience and text can no longer be presumed. He argues that "lived texts are representations that are themselves embodied representations of experience" (Denzin 1997:33) and that "real-life experiences are shaped by prior textual representations" (Denzin 1997:33) in the following way.

“These experiences are in turn shaped by understandings gained from participating in the performances of others – performances turned into texts.

These understandings, in turn, are reinscribed in the transcribed voice and dialogue of the other. They are created in the social text. These texts are dialogical, the site at which multiple voices co-mingle. In them, the voices of the other, and the voices of the researcher, come alive and interact with one another. These accomplishments have a prior life in the context in which they were produced—a life and a form that can never be fully recovered” (Denzin 1997:33).

4A.5.2. Text as a parallax of discourses

Bakhtin explained that there can be neither a first nor a last meaning because of the existence of a chain of meanings (Bakhtin, 1986). He anticipated the postmodernist text as a text based on a parallax of discourses in which nothing is ever stable or capable of firm and certain representation (Bakhtin, 1986). The conclusion drawn by Denzin was that discourses always occurred for the first time and could not be repeated. Every time an attempt was made to repeat a discourse, it was in fact a new discourse that was created with a meaning that would be different.

Text should therefore not be understood to be subjective accounts of experience. Instead, they “attempt to reflexively map multiple discourses that occur in a given space” (Denzin 1997:xvii). Because texts are multivoiced, no given interpretation should be privileged and the principle of textual autonomy is contested.

4A.5.3. Logocentric bias

Denzin challenged the commonsense view in which writing was considered “a form of communication where, through the use of language, words, phrases, and often sentences, a writer conveys meanings and understandings”, which implied that a written text is a “bounded unit of meanings” and that its “meanings are clearly discernible” (Denzin 1989:44). Denzin explained what he concluded to be a logocentric bias in the following way:

“If words are only made up of difference – if signs have no stable meanings, but only exist in transformations and traces – then texts have no center or essential structure. However, stories and texts are written ‘as if’ they do have centres. Thus, writers and readers presume and ‘read into’ texts real authors, real intentions, and real meanings” (Denzin, 1989:45).

4A.6. The impact of using critical post-structuralism on the study

The combined impact of the issues that were summarised above result in what Denzin identified as an epistemological bias in modernist reading and writing of qualitative research. My own opinion, formed on the basis of readings presented throughout this chapter, is in agreement with post-modernist views that make strategies with which to achieve the criteria *dependability*, *transformability* and *confirmability* redundant. In fact, I believe that no claims can be made of a truth that will remain stable. Two obvious elements that, in practical terms, contribute to this view are given by way of illustration:

- ◆ Influences on the work-lives of people with psychiatric disability will change as the meso and macro environments change over time.
- ◆ The influences identified and presented are the result of many layers of construction and interpretation. For example, participants first interpret for themselves the meaning of the question asked, then construct an

answer that reflects their interpretation of what a good answer would be. Understanding of such an answer is now informed by the listener's own existing knowledge and ability to listen and understand. These processes occur even before analysis and interpretation strategies that follow and their complexity cannot be captured. The nuanced interactions that characterise interviews that work well cannot be captured between the words of transcribed interviews, no matter how carefully these are done. Instead, they are captured in the understanding of the researcher and participant and will inform answers to research questions.

I believe the issue of representation to be tied in with the legitimacy of interpretive processes. Post-positivist views and descriptions of procedures have prescribed a close alignment with the actual words and observations that are recorded as 'real' representations of experience. Such views draw into question the legitimate foundation for interpretation because the researcher is bound by their transcripts and field notes as the only 'real' evidence for understandings yielded.

A conclusion to the crises of representation and legitimation could be drawn, quite simply, in Denzin's words:

"Stories then, like the life they tell about, are always open-ended, inconclusive and ambiguous, subject to multiple interpretations" (Denzin, 1997:81).

4A.7. Locating the nature of truth

To establish answers to the research questions obviously would imply a process of finding truth; a concept that is not easily captured. The numerous, deeply philosophical, arguments that debate the nature of truth bear testimony to the complexities of the concept under consideration. Denzin

concluded an in-depth discussion of the standards of truth in an autobiographical work by making it clear that it is necessary to do away with a distinction between fact and fiction (Denzin, 1989:25). He explained why there was no basis on which types of truth could be differentiated. The reason for this problem was tied into an acceptance that a clear differentiation between three concepts, namely facts, facticities and fiction, cannot be made (sic) (Denzin, 1989:23-25). This view of truth was adopted to guide action in the present study. Care was taken to scrutinise experiences that were shared for their meaning and coherence within the lives of participants sharing their stories. The place and purpose of an event, and its significance in the life of the storyteller remained the focus of attention, instead of an attempt to find collateral in order to confirm that such an event had actually taken place. For example, Joanne felt that her behaviour was incorrectly ascribed to having a bipolar mood disorder when, in her own mind, it was the result of going through a difficult divorce. Joanne experienced her work context as critical and unforgiving, leading to her decision to apply for termination of her employment as a psychiatric nurse, on medical grounds.

4A.8. Post-modernist thinking and the use of biography

My interest in using biographies in the research project came first; then it became necessary to read in order to situate the study meaningfully and coherently within the realm of post-modernism. Previous readings of post-modernist thinking were not done for the same purpose. Plummer argued for the rise of post modern sensibilities by linking them with a heightened interest in 'stories' and 'narratives'. He argued for "the need for *grounded, multiple and local studies of lives in all their rich flux and change*" (Plummer, 2001:13 emphasis in original).

These characteristics captured what was needed in a design that would best answer the research question of the present study. The decision to utilise a

design that is situated with post-modernist thinking was confirmed by these characteristics. However, the main reason was its reliance on the life stories of participants. My decision to use an interpretive biography design replaced my very early idea, which was to do a grounded theory. The main reason for this change was my understanding that interpretive biography would allow for more emphasis on participation and more freedom for interpretation; strategies that are in keeping with understanding people holistically. I was interested in intersubjective knowing which demands engaging with others around their experiences.

4A.9. Situating the study

I mentioned elsewhere that my original intention was to answer the research question with the use of grounded theory. This initial idea was abandoned because of my concerns with:

- ◆ the seemed rigidity of the methodology.
- ◆ the fragmentation of data into micro elements that, to me, seemed contradictory with the intention to obtain a comprehensive picture of influences that emerged inductively. In other words, it seemed to me that grounded theory methodology would be better suited to answer questions about why a particular influence had a specific impact rather than giving the type of coverage that I sought for.
- ◆ right from the start I felt a resistance against discarding particular influences because they were not verified in the experiences of others or in the literature. This had something to do with the marginalisation of people with psychiatric disabilities. By the same token I resisted a situation wherein the need would arise for the knowledge produced in the South African context to be grounded in literature produced in countries with very different contextual realities.

I considered interpretive biography as an alternative, and reading about this methodology pointed me to readings that were post modernist and/or post structuralist in nature. It is only within postmodernist thinking that this study could be situated and given the freedom to claim that understandings gained were in fact worthy findings – because such findings were indeed as ‘unimportant’ as any other sets of research findings produced elsewhere in the world. In fact it is my belief that post modernist emphasis on producing contextually relevant, small scale studies that do not try to be more than they are allows the impetus for researchers in the developing world to explore their own contexts. It not only provides strong arguments against claims made by grand theories but succeeds to foreground the inappropriateness of some claims made by researchers about contexts of which they do not have experience.

As a point of departure the roots of life history research, from which interpretive biography methodology evolved, within anthropology (and specifically ethnography) should be acknowledged. However, when tracking the development of interpretive biography methodology as it is used in this study it should be acknowledged that the ontological foundation moved to fit more closely with symbolic interactionism. At the same time, the broad and diverse development within ethnography has been such that a claim can be made for a comfortable fit of interpretive biography methodology within ethnography. This would however only apply where a postmodernist stance is taken; such as is the case in interpretive ethnography.

Lincoln summarised the general use of qualitative research methods as follows:

- ◆ to grasp phenomena in a holistic way,
- ◆ to understand phenomena within context, or
- ◆ to emphasize immersion in and comprehension of human meaning.

She described it as the method of choice “for most forms of anthropology, for much of sociology, for ethnography or for any kind of research that

emphasizes broad understanding and deep insight over shorthand or reductionist data" (Lincoln, 1992:376). Lincoln separated what she termed "conventional qualitative methods" (Lincoln, 1992:377) from constructivist methods¹⁶ that emphasise holism. She highlighted the ontological stance of constructivist research as being that "realities are constructed entities" (Lincoln, 1992:379), and emphasised the subjective nature of its epistemology. The consequence is that findings are literally created from a process in which "the inquirer and the inquired-into are merged into a single, interactive entity" (Lincoln, 1992:380). The strongest argument for the use of constructivist methods in health research is an acceptance that health is a human construct; largely made up of human behaviours that are, in turn, strongly influenced by attitudes, belief systems, values, mental and psychological constructs of health and individual actions (Lincoln, 1992).

Lincoln held the view that constructivist methodology is hermeneutic in nature because "individual constructions are elicited and refined through iterative interactions between and among investigator and respondents" (Lincoln, 1992:380). She placed grounded theory in the domain of constructivism, singling it out as making contributions that cannot be made any other way.

Alvesson and Sköldbberg took a different stance shown by their separation of hermeneutics from data-orientated methods which comprised grounded theory, ethnomethodology and inductive ethnography (Alvesson and Skoldberg, 2000). They labelled these methods 'hyper-empiricist' because of their structured nature, strict guidelines and the tendency to work "in close proximity with data" (Alvesson and Skoldberg, 2000:48). Their criticism of data orientated methods was captured as follows:

"These currents miss the main part of the interpretive problematic, so that the data appear as more or less unmediated, pure, and the research process is endowed with a naïve character of gathering and

¹⁶ Lincoln equates what is called the "constructivist" view in the discipline of psychology with what other disciplines refer to as the "naturalistic" paradigm

threshing empirical material according to some sort of agricultural metaphor" (Alvesson and Skoldberg, 2000:48 & 49).

4B.9.1. The influence of hermeneutics

Hermeneutics holds as a point of departure the interpretation of texts, or exegesis, with the main theme being that "*the meaning of a part can only be understood if it is related to the whole*" (Alvesson and Skoldberg, 2000:53) (Italics in original). Hermeneutics propose solutions to the apparently unsolvable contradiction of the so-called hermeneutic circle (that parts can only be understood from the whole, and the whole only from the parts). Attention is initially focussed to some part, insights gained are then tentatively related to the whole upon which new insights are gained; focus is again returned to the part studied.

"... you start at one point and then delve further and further into the matter by alternating between part and whole, which brings a progressively deeper understanding of both" (Alvesson and Skoldberg, 2000:53).

The circle of *objective* hermeneutics consider the relationship between the part and the whole as explained above. Alethic hermeneutics advocates a different cycle, one that considers the tension between preunderstanding and understanding.

"The common trait of the hermeneutic circles (and more than two are conceivable) is that they present a processual, dialecting solution, alternating between the poles in a contradiction which at first sight, and regarded statistically, seems unsolvable" (Alvesson and Skoldberg, 2000:54).

Alvesson et al. explained how the interpretation of understanding within hermeneutics increasingly expanded to include *empathy* - the ability to imagine oneself in the author's place in order to understand the meaning of the act more clearly (Alvesson and Skoldberg, 2000). Empathy is not accessible to an individual attempting to analyse texts from the outside and contains a "creative, non-rule-bound aspect" (Alvesson and Skoldberg, 2000:54). Another ingredient that was emphasised is *intuition*.

"Knowledge is not to be acquired in the usual, reasoning and rational ('discursive') way. There is instead something of a privileged royal road to true knowledge of the world. This is achieved, not by laborious pondering, but rather at a stroke, whereby patterns in complex wholes are illuminated by a kind of mental flashlight, giving an immediate and complete overview" (Alvesson and Skoldberg, 2000:52).

Interpretive processes that are characteristic of hermeneutics were used in the present study. Understandings gained through interpretation of the whole text were successively developed by the interpretations of its parts whilst those parts were understood in the light of unfolding insights about the nature of the whole. The researcher determines what constitutes the part and the whole; shifting these concepts as required. Examples were:

- ◆ the individual experience of a participant (part) was understood more clearly when considered in the light of combined experiences of other participants within the mesa and macro environment (whole),
- ◆ a single event in the life of a participant (part) was understood against the insights that emerged when looking at the biography of the same participant (whole) or
- ◆ a particular theme, for example the impact of disclosure (part) was understood against the joint experiences of the same theme constructed across all participants.

This process mirrored the second hermeneutic cycle; that of an alternation between preunderstanding and understanding.

“Understanding constitutes a creative, re-productive act, in which the researcher appropriates the meaning of the object, rather than mechanically mirroring it. The researchers carry around their own frames of reference, also the reason why interpretation always possesses only a *relative* autonomy, never an absolute one” (Alvesson and Skoldberg, 2000:68).

Initial ideas were held tentatively, to be considered at a later stage or scrutinised some more until some confirmation was found for such ideas to be accepted with more conviction. Special care was taken to ‘verify’ those understandings that were held at the start of the study. Through analysis and interpretation such understandings were given a provisional status and special care was taken to scrutinise texts for supportive evidence. In one such example the value of participation in work was understood. At the onset of the research a tentative belief that people with psychiatric disability will in fact benefit directly from participation in work, not only from the advantages of earning an income, was based mostly on occupational philosophical concepts, societal attitudes towards work and personal experiences of being a worker. I guarded against my natural occupational therapy tendency to develop understandings about the value of work unless such was evident in the texts. Understandings were therefore given the status of preunderstanding in order to ensure an open mind with which new understandings could be developed. Another example was an understanding with which the research was undertaken; a belief that the stigma of psychiatric impairment would in most cases lead to direct discrimination in the work place. The influence of disclosure on the person who disclosed and on the person/people to whom he/she disclosed was scrutinised in much detail. Preunderstandings (changes in behaviour following instances of disclosure) were further considered, followed up and pursued in subsequent interviews with participants; then

considered in the light of developing preunderstandings gained from other texts in order to move towards understanding.

4B.9.2. The place of bias

This discussion will be started with an exploration of the term bias. Firstly, it is believed that authenticity of research findings might be reduced because of researcher bias. A second consideration would be the impact that source bias might have on the authenticity of the findings. Source bias has been defined as “the interest (conscious or not) of the informant in skewing the information” (Alvesson and Skoldberg, 2000:72). Both these considerations are problematised by the ontological stance of post-modern work and the interpretive biography methodology. Denzin concluded an in-depth discussion of the standards of truth in autobiographical work by making it clear that it is necessary to do away with a distinction between fact and fiction (Denzin, 1989:25). He explained why there is no basis on which different types of truth can be differentiated. Denzin’s advice on this matter can be summarised in his words “if an author thinks something existed and believes in its existence, its effects are real” (Denzin, 1989:25). This view of truth was adopted to guide action in the present study. However, care was taken to scrutinise experiences that were shared for their meaning and coherence within the lives of participants sharing their stories. The place and purpose of an event, and its significance in the life of the storyteller remained the focus of attention, instead of an attempt to find collateral in order to confirm such an event. The achievement of intersubjective knowledge was the expressed goal of the present research. Therefore, findings could not be ‘contaminated’ by the introduction of experiences or views that related to experiences of participants and/or the researcher in ways that definitions of bias would suggest.

4B.9.3. Problematising Life History research

Hammersley raised two major problems of life histories research. The first was the problem of representativeness or typicality; in other words, that findings obtained through life histories research cannot be generalised. The second problem was that life histories research is time consuming or, in Hammersley's words "...a considerable undertaking. With low guarantees of generalizable findings" (Hammersley, 1984:137). Hammersley emphasised the negativity of these considerations for the development of Sociology as an academic discipline; an argument that would be based on an assumption that academic disciplines gain most benefit from research endeavours that produce generalisable findings. It is my opinion that such an assumption does not hold when:

- ◆ very little empirical knowledge has been generated to inform thinking,
- ◆ contexts are very different from those in which available knowledge has been produced and
- ◆ when research findings are required to inform practice in a particular context, rather than only contributing to the existing body of knowledge.

The production of context specific knowledge might therefore be understood to be equal in value, or even more valuable, when consideration is given to the ultimate purpose of the research. Even when this argument is not accepted, it will often be the only starting point.

"Ultimately we may be more interested in a phenomenon or a population of cases than in the individual case. We cannot understand this case without knowing about other cases. But while we are studying it, our meagre resources are concentrated on trying to understand its complexities." (Stake, 1998:87)

It is balanced by the need for contextually appropriate knowledge in the South African context. It is also balanced by the fact that research done to

explore factors that promote or hinder work participation of people with psychiatric disability has predominantly been positivist research.

4B.9.4. The influence of Postmodernism and Poststructuralism

Post modernists and particularly poststructuralists question the humanist idea of a single subjectivity, "which at any given moment is fixed and complete, as a Western invention" (Alvesson and Skoldberg, 2000:164). The dominating notion of the individual is decentred; emphasis is placed on linguistic and discursive context "which socially creates forms and expressions of subjectivity limited in time and space" (Alvesson and Skoldberg, 2000:164). In other words, language is not merely an expression of subjectivity - it constitutes subjectivity.

The use of language triggers thoughts, ideas and emotions. From this it follows that subjectivity is something unstable, contradictory – a process rather than a structure (Alvesson and Skoldberg, 2000:164).

Attempts to differentiate between postmodernism and poststructuralism have shown the difficulties encountered when trying to make a distinction and are of limited value (Alvesson and Skoldberg, 2000:150). Rosenau asserted the difference to be that "post-modernists are more oriented towards cultural critique while the post-structuralists emphasize method and epistemological matters" (Rosenau, 1992:3). She also wrote:

"Most of what is written here with reference to post-modernism also applies to post-structuralism. Although the two are not identical, they overlap considerably and are sometimes considered synonymous. Few efforts have been made to distinguish between the two, probably because the differences appear to be of little consequence" (Rosenau, 1992:3).

4B.9.5. Justification for relying on postmodern and poststructuralist thinking

Rosenau summarised the focus areas of post modern scientists to be a re-focusing on what has been taken for granted and what has been neglected; including the irrational, the insignificant, the repressed, the borderline, the rejected, the nonessential, the marginal, the peripheral, the excluded, the tenuous and the silenced (Rosenau, 1992).

“The emergence of post-modernism may simply reflect intellectual currents in the larger society, but in the social sciences it also reacts to uncritical confidence in modern science and smugness about objective knowledge” (Rosenau, 1992:9).

Application of natural science models to the study of society has been a major point of criticism for postmodernists. Rosenau argued that the positivist empiricist, rational-logical model of modern science paradigm maintained its position while consensus prevailed. This consensus was however always vulnerable; the arrival of postmodernism coincided with an era in which apparent inadequacies of modern science was being foregrounded. She included the following criticisms of modern science in her discussion:

- ◆ expectations had been inflated and promises unfulfilled
- ◆ that research in some instances led to abuse and misuse
- ◆ in some cases it legitimated the preferences of powerful, justified normative positions that were mere preferences rather than ‘scientific facts’
- ◆ results were used in an ad hoc fashion to “‘prove’ the value of subjective political policy preferences” (Rosenau, 1992:10)

The criticisms raised here have been dominant in psychology and psychiatry - to the disadvantage of people with mental health concerns in general and

specifically those with psychiatric impairment. The intention and outcome of research within a modernist framework tends to use a static and predictability of 'normality' as a point of departure for the development of assessments and classifications that served to highlight 'abnormality' without consideration to diversity of experience. At the same time cultural influences that were notably different from the Western generalisation of norm were considered to be extraordinary and separated from the norms through the use of labels that suggested them as being exotic or mysterious.

The appeal of postmodernism includes its open-endedness and lack of specific definition that is at once attractive to the affluent, the desperate and the disillusioned of this world. Rosenau concluded that postmodernism has become synonymous with inquiry itself in many areas of humanities "so much that its nomenclature need not be made explicit" (Rosenau, 1992:12)).

Postmodernism comprises two broad (general) orientations that are divergent, even contradictory; the 'skeptical' postmodernists and the 'affirmative' postmodernists. Sceptical postmodernists (or merely skeptics) draw their inspiration from Continental European philosophies, that include Heidegger and Nietzsche, and are concerned with the dark side of postmodernism, "the post-modernism of despair, the post-modernism that speaks of the immediacy of death, the demise of the subject, the end of the author, the impossibility of truth, the abrogation of the Order of Representation" (Rosenau, 1992:15). Affirmative postmodernists (or affirmatives) agree with the critique of modernity but hold a more hopeful and optimistic view of the post-modern age. Affirmatives are either open to positive political action or content with the recognition of visionary, celebratory personal nondogmatic projects across a broad spectrum of social movements; their intellectual practice remain nondogmatic, tentative and nonideological (Rosenau, 1992). Both the domains of affirmative and skeptical postmodernism cover the full range of extreme to moderate versions distinguished by "the intensity of their opinion and their willingness to carry

their post-modern conviction to its most extravagant, excessive conclusion – no matter what the outcome or consequences (Rosenau, 1992:16).

The influence of postmodernist thinking on the construction of truth in this project was informed by my own reading of the futility of attempts to achieve a 'stable', 'valid' and thus generalisable set of findings. Intellectual productions that necessarily involve the exclusion of experiences that fall outside 'norm' behaviour, in order to ensure generalisability, did not contribute the types of knowledge that were required. Most research available for reading had been generated in developed countries and with samples that therefore resembled a small minority of the South African population (i.e. those with access to services). A mindset that transforms authoritative claims of truth into tentative suggestions that might have application value in some contexts was therefore developed. The work presented here will violate many postmodern guidelines for inquiry, especially those aligned with sceptical postmodernism and all with extreme orientations. The focus of the study undertaken was not to contribute to postmodernism per se; but to give careful consideration to contextually situated influences that might shape the participation of people with psychiatric disability in particular ways. The contribution of postmodernism allowed for liberation from approaches that would judge the value of research by the extent to which the outcome achieved is 'grounded', objective, repeatable or validated. These notions have been repeatedly problematised by researchers and practitioners who operate in diverse and fluid contexts in which applicability of research evidence is always considered tentative and provisional.

The reader might rightfully situate the project as (merely) 'interpretive' in nature. Such a reading would sit comfortably with my own situation of the study, with a proviso that the reader takes cognisance of the postmodern influence that necessarily shifts the work outside the domain of hermeneutics (that holds the elimination of subject bias and the establishment of validity as realistic outcomes). The project would as such not be situated unusually:

"Because the very term post-modernism has come to represent controversy and criticism, many post-modernists avoid the label. Some argue that the word post-modern promotes a singular view of reality, encourages closure, and denies complexity. So they retreat from it to avoid its pejorative associations as something bizarre and frivolous. They refer to themselves in less contexted terms, such as post-contemporary. Or they might suggest their work is merely 'interpretative'" (Rosenau, 1992:17).

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Section B: Introducing interpretive biography and the use of narrative

Introduction

Interpretive biography, as a research design, is interactive and participative, which is particularly suited to a study of this nature. I had to be sure that the participants were able to play their role as partners in the co-construction of data and, to some extent, in processes of analysis. I expected the research question to require the type of answers that people do not always have 'ready made' in order to give. The design therefore had to allow for the sharing of experiences (of the type that also has a temporal dimension to it) and for the outcome of such sharing to provide a holistic picture of experiences that could be put together to inform interpretation. I do not mean that I expected participants to lack insight, to not know what is best for them or that they were not 'high functioning' enough. It was understood that research participants could not always be expected to provide direct answers. I was also interested in what was not said in the context of an unfolding life story.

4B.1. Historical developments

Significant developments took place in life story work from the early 1980s onwards. The use of life stories has had multiple roots that can be followed through to the present (Plummer, 2001). Significant advances have been associated with a group of sociologists who worked in Chicago during the twenties and thirties (Bertraux, 1981, Plummer, 2001 #104; Plummer, 2001). By the forties the technique had lost its appeal and American sociologists (considered to be leaders in the field of Sociology at the time) had almost completely abandoned the use of life stories. "Its collapse was as sudden and radical as had been its success and prestige during the twenties" (Bertraux,

1981:5). Bertaux suggested that those who wish to use life stories for social research should come to grips with the reasons for this collapse in order to confront doubts about the future viability of the technique. He identified the causes for the collapse as being 'social' and 'methodological' and drew attention to the fact that all the Chicago studies were designed within one particular theoretical framework namely 'symbolic interactionism' and that the studies all focussed on "a particular set of social processes under the general heading of 'deviancy'" (Bertraux, 1981:5). The main theoretical issue, according to Bertaux, should be the "connection between social dynamics and historical change" (Bertraux, 1981:6) and the question to ask "what is the relationship between individual and collective praxis and sociohistoric change?" (Bertraux, 1981:6).

Ferrarotti made a strong claim for the biographical method as an "alternative meta-mechanistic, methodological approach" (Ferrarotti, 1981:20). This claim would have been influenced by Ferrarotti's own move away from what he referred to as survey research. The participation that inevitably characterised the relationship between the teller of the story and the researcher was emphasised by Ferrarotti as an important defining characteristic of the biographical method. The synthetic character of autobiographical narratives was also highlighted by Farrarotti (Ferrarotti, 1981).

4B.2. The nature of interpretive biography

Denzin categorised the guidelines that have been proposed for the ordering and interpreting of life history, life story, autobiographical and biographical materials by first of all differentiating between objective formats and interpretive frameworks that work from the subject's point of view. His own reading of the use of biography and autobiography draws on an interpretive framework. Denzin described interpretive biography as "the studied use and collection of personal-life documents, stories, accounts, and narratives which

describe turning-point moments in individuals' lives" (Denzin, 1989). Objective and subjective markers reflect key critical moments through which existence can be "mapped, charted and given meaning" (Denzin, 1989).

Interpretive Biography as a method is best understood when looked at in combination with similar methods that share the same roots. Bertaux explicated the differences between 'life story' and 'life history', suggesting that a distinction between the two "might well involve a distinction between two different approaches" (Bertraux, 1981:7). Life story is defined as an "account of a person's life as delivered orally by the person himself" (Bertraux, 1981:6). A life history is a life story with additional biographical information included into it. This distinction is unnecessary when a differentiation between fact and fiction is not made. Denzin described autobiographies and biographies as "conventionalized, narrative expressions of life experiences" (Denzin, 1989). The subject matter best described by using interpretive biography are the experiences of people (Denzin, 1989).

In this research project, narratives that focussed on work were constructed by participants with the facilitation of the researcher. In the telling of their stories, key events and turning points were highlighted by participants. The stories obtained could therefore be categorised as 'edited short life stories'.

4B.3. The philosophy of (auto)biography and the self

Concepts under scrutiny when interpretive biography is used include three components of life stories. The three components were explained by Plummer as "autos (what do we mean by the self?), bios (what do we mean by the life?) and graphe (what do we presume in the act of writing?) (Plummer, 2001:86 italics and brackets in the original). Complex philosophical explanations of these concepts shape the views held about the nature of truth that can be obtained through the use of life story work.

Users of the biographical method operate on the assumption that the inner life of a person can be captured in the biographical document (Denzin, 1989). My own use of this method was confirmed because of this characteristic. The lives of participants contained rich information that was at the same time appropriately situated within the South African context. Participants were all in the process of living their lives and therefore able to relate their experiences of success or failure in their attempt to participate in work. When participants shared their stories, they made no attempt to differentiate between deep and surface levels, but in the telling of the stories their interrelatedness became clear.

When a life is written about, an attempt could be made to cover the entire story of such a life, or a particular section, topic or set of experiences could be selected. Bruner made a distinction between a life as lived, a life as experienced and a life as told:

“A life lived is what actually happens. A life experienced consists of the images, feelings, sentiments, desires, thoughts, and meanings known to the person whose life it is. . . .A life as told, a life history, is a narrative, influenced by the cultural conventions of telling, by the audience, and by the social context” (Bruner, 1984:7).

This distinction is presented together with a conclusion that there will always be inevitable gaps between reality, experience and expression. Advice is given that the researcher should remain alert to such gaps, and sensitive to the ways in which people might fill them in. I found that the gaps left during the telling of stories were often very significant. More detail will be given about this when construction of data is discussed.

4B.4. Conventions of biographical and autobiographical methods

Denzin shared critical points concerning autobiographical and biographical methods. These are discussed below together with explanations of the attempts made to scrutinise and counteract the possible impact of the conventions of the biographical method on the quality of the data produced in this study.

4B.4.1. The existence of others

Denzin held the view that "biographical texts are always written with an 'other' in mind" (Denzin, 1989). In this study, participants knew that they were telling their story to a researcher with an interest in promoting equity and participation of people with psychiatric disability in work. In the researcher's mind the 'other' was an intellectual community of policy makers and service providers. The presence of the 'other' would inevitably influence the prominence given to key events, both in the telling of stories and in the interpretation of the meaning of such events. The process of constructing (and interpreting) a narrative, with the 'other' in mind, would lead to a re-appraisal of key events, foregrounding those aspects in which the 'other' is deemed interested. The dynamic process of telling a story with an 'other' in mind would inevitably require a re-conscientisation of what is considered pertinent and relevant. The information that was included in the telling of life stories was understood with the above mentioned tendency in mind. Attention was therefore also given to what was not said, and to the prominence given to those aspects that were shared.

4B.4.2. The influence and importance of gender and class

Denzin highlighted that biographical texts “are gendered, class productions, reflecting the biases and values of patriarchy and the middle class” (Denzin, 1989). People with psychiatric disability are usually assigned to a distinct social group within society; one that is often misunderstood, sometimes feared and almost always marginalized. Such a linkage to a group with a reduced social standing could be expected to have an impact on the identity construction of its members. In this study, participants’ narratives situated themselves closer or further away from the social disenfranchised group of people with psychiatric disabilities. In so doing, the reality of being associated with such a group influenced their identity construction to a larger or lesser extent.

The fact that the researcher did not belong to the group would have contributed to power imbalance in the relationships formed. Careful attention had to be given to move beyond a tendency to position people with psychiatric disability, and those without, in two groups that are legitimately different. Further care had to be taken not to reinforce the power imbalance that inevitably characterise relationships between researcher and participant, but that was magnified because of dynamics at play between people with psychiatric disability and those perceived to be in the helper role. This issue will be discussed in more detail in Section C.

4B.4.3. Family beginnings and starting points

The tendency, when biographies are written, is that the production will start in family history (Denzin, 1989). However, the tendency in this study was for participants to initiate biographies at the point of their first experience of psychiatric impairment. This was an interesting departure from the usual

convention, one that might point to the severity of disruption experienced by participants when they first experienced psychiatric impairment.

4B.4.4. Known and knowing authors and observers

Participants shared their stories with an expectation that the researcher had particular knowledge and attitudes about work and psychiatric disability. Such an awareness would naturally shape the content and emphasis of participants' narratives as explained earlier. Denzin highlighted the assumption that the self, or writer, "knows his or her life, and hence is in the best position to write about it" (Denzin, 1989). In the context of this study, participants were in the position of author, even though they were telling their story to the researcher who ended up writing the story. While the researcher initially took on the role of observer, this role changed to that of author, with service providers and policy makers in mind as observers.

4B.4.5. Turning point experiences

"The notion that lives are turned around by significant events, what I call *epiphanies*, is deeply entrenched in Western thought" (Denzin, 1989:22 Italics in original). Most authors accept the convention that turning point experiences signal significant moments in the lives of people. In this research project participants structured their stories by highlighting episodes in which new work was found, work was lost and prolonged episodes of no work. Other epiphanies seemed to be closely linked with their experience of 'breakdowns' and periods of hospitalisation.

4B.5. Analysis of narrative and narrative analysis

Polkinghorne detailed the assumption that narrative is one of the operations of the realm of meaning and that examination of this realm would aid in the understanding of narrative (sic). He concluded that:

"...narrative meaning is one type of meaning produced by the mental realm. It principally works to draw together human actions and the events that affect human beings, and not relationships among inanimate objects. Narrative creates its meaning by noting the contributions that actions and events make to a particular outcome and then configures these parts into a whole episode" (Polkinghorne, 1995:6).

Polkinghorne explained how the term *narrative* is used by qualitative researchers with a variety of meanings (Polkinghorne, 1995). He suggested that narrative within *narrative* inquiry was "a discourse form in which events and happenings are configured into a temporal unity by means of a plot" (Polkinghorne, 1995:5). He presented Bruner's classification of narrative inquiry into two distinct groups, namely narrative analysis and paradigmatic-type analysis (Polkinghorne, 1995:5). The details of these two forms of analysis are depicted in the Figure 4.1. below.

Figure 4.1: Differences between narrative analysis and paradigmatic-type narrative inquiry

Paradigmatic-type narrative inquiry	Narrative
"..operates by recognizing elements as members of a category"	"..operates by combining elements into an emplotted story"
".. gathers stories for its data and uses paradigmatic analytic procedures to produce taxonomies and categories out of the common elements across the database".	"..gathers events and happenings as its data and uses narrative analytic procedures to produce explanatory stories".

Polkinghorne built on Bruner's classification to draw a clear distinction between (a) analysis of narratives and (b) narrative analysis. The first refers to studies in which the data consist of narratives that are then analysed to produce categories. The latter refers to "studies whose data consist of actions, events, and happenings but whose analysis produces stories" (Polkinghorne, 1995:6). The process of analysis followed in this study involved both these categories of analysis.

Dominant strategies used in analysis were in line with traditions of narrative analysis. Both approaches discussed above were used in tandem throughout the period of data collection. This allowed for a balance between analysis processes and interpretative processes, and created a mechanism to move between analysis and interpretation. Savin-Baden warned against an over-structured approach to analysis:

"It seems to be a process of structuring the messiness of data so that data seem, at least for a while, manageable. The danger, however, with analysis is to over simplify, to develop bland categories that are a 'catchall' for most of the issues that people raise. This oversimplification can be compounded by the use of computer packages that tend to break things down into detailed themes and words that result in deconstruction rather than

reconstruction of the data. By listing themes we then tend to fit what people said to these, rather than actually letting complexity emerge” (Savin-Baden, 2004).

The use of *narrative analysis* predominantly contributed to the development of themes while the *analysis of narratives* ensured comprehensive coverage of all influences that were inherent in the data.

University of Cape Town

Section C: Situating the study

Introduction

Theoretical constructions that were introduced in the previous two sections guided my decisions on how to conduct the research. The process used to conduct this study will be discussed in this section.

4C.1. Aim

The aim of the study was to explore the influences that impact on the work-lives of people with psychiatric disability.

The basic assumption that served as a point of departure was that an interplay of influences either foster or hinder the ability of people with psychiatric disability to participate in the world of work. Such influences would exist in micro, mesa and macro environments. A further assumption was that such influences would form part of the lived textuality of people with psychiatric disability, experienced as turning-point moments (or epiphanies). A third assumption made was that such epiphanies would be included by participants in the construction of their life story.

4C.2.Purpose

Mental health policies that currently do not give sufficient attention to the promotion of work as a strategy might be challenged. Importantly, all findings presented in the study will reflect the South African context. Findings could directly inform reasonable accommodation and the development of affirmative action programmes. Knowledge about the influences that emerged from this study could inform service providers, specifically to guiding their focus (i.e.

less focus on medical condition), type of programme (i.e. health promotion) and choice of strategy (i.e. supported employment). It could also be used to assist with service developments that interpret and promote the implementation of labour legislation intended to equalise work opportunities for psychiatrically disabled people. It is also hoped that the research will challenge the many stereotypes that shape decisions made about the ability of people with psychiatric disability to contribute to society through their participation in work.

4C.3. Study Population

The study population comprised people who have a psychiatric impairment that would fit prominent diagnostic categories represented on Axis 1 of the DSM IV Classification and who live in the Western Cape. However, people with diagnostic categories that have an element of being self-induced, such as Substance-Related Disorders and Eating Disorders were not included in the study. This decision was informed by an assumption that different sets of influences would be impacting on participation in work. Employers might for example behave differently. Importantly, people with these impairments are usually seen to have it in their control to prevent active symptoms in the workplace. What I mean is that someone with a substance-related disorder would be expected not to use such substances at work. This is different from symptoms associated with other impairments, for example schizophrenia.

The research provided an opportunity to meet people with psychiatric disability in contexts that were very different from the ones I had been working in as an occupational therapist. Now, rather than seeing people in need of help within a medical world that was constructed by health professionals to 'fix' patients, I saw functioning people in their natural context. More importantly, I was the one seeking help this time. The experiences of participants were crucial in a process designed to understand

what needed to be done in order to improve the participation of people with psychiatric disability in work. The focus of the interviews was to better understand research participants as workers. The contexts in which the interviews took place were varied, but for the most, these provided a window into the environments within which participants lived their lives.

4C.4. Ethical Considerations

4C.4.1. Respect for participants

The right of participants to exercise their autonomy was protected through the use of:

- ◆ informed consent,
- ◆ confidentiality, and
- ◆ the value assigned to participation.

Obtaining informed consent is one of the most obvious and significant strategies used in order to ensure ethical research practice. Davies concluded that information remains the keystone of informed consent (Davies, 2001). However, special consideration was given to the process used to obtain consent. This was necessary to safeguard participants against the power imbalance that inevitably exists between people with psychiatric disability and rehabilitation professionals. The result of such a power imbalance could be that the potential participant, when approached to participate, is not able to refuse. For this reason, initial provisional consent was obtained by a known (and trusted) service provider who approached that potential participant on behalf of the researcher. Names and contact details of potential participants were supplied to the researcher after they had expressed an interest to participate in the study.

When participants were contacted to set up the first interview, it was made explicit that the meeting would be used to further explain the research and to answer questions that potential participants might have had. It was explained to potential participants that they would then be asked to make a decision about participation.

At the start of the first meeting the purpose and nature of the study was explained, as well as detail about what would be expected from participants. Clients were made aware that they were at liberty to withdraw from the study at any time.

4C.4.2. Beneficence

Participants were informed that no direct benefit would be gained from their participation in the study. However, the purpose of the study was explained as being 'to inform practice and/or guide the implementation of legislation'. The mention of this purpose often led to a discussion in which participants welcomed an opportunity to 'do something' for people with psychiatric disability in general.

It should be noted that most participants did find the interviews beneficial. They often expressed their view that the interviews had been valuable. This benefit was attributed to several aspects; they valued an opportunity to tell their story, to be listened to, enjoyed being asked their opinion and found that the interview questions elicited a fresh perspective. Some of the participants who had been in psychotherapy for many years even commented that the interviews had led them to look at their lives differently.

4C.4.3. Non-maleficence

Stake cautioned qualitative researchers that they are “guests in the private spaces of the world” (Stake 1994:244). At times during the interviews participants would share experiences and feelings that were difficult to speak about. Feelings of sadness or shame, or frustration and anger were mostly expressed during these times. At no stage were these emotions a cause for concern. Care was taken, throughout the process, to avoid low-priority probing of sensitive issues.

4C.5. Participants in the study

4C.5.1. Sampling Strategy

Purposive sampling, in particular maximum variation sampling (Patton, 1987), guided the process used to obtain participants for the study. Firstly, variation was sought with regards to diagnostic category. This was done because of a general tendency to link ability to work with diagnostic categories. Variation in terms of population group was considered important because of the past apartheid policies that legislated the opportunities available to different groups of South Africans. The suburb, or community, in which participants resided, would also point to inequalities, for example, the availability of health services.

Table III: Participant profiles in terms of language, suburb, diagnostic category and population group.

Pseudonym	Language	Suburb	Diagnosis	Population Group
Sipho	IsiXhosa	Khayelitsha	Schizophrenia	African
Jessica	English	Wynberg	Bipolar	White
Suzaan	English	Wynberg	Bipolar	Coloured
Donovan	English	Elsiesrivier	Bipolar	Coloured
Robert	English	Pinelands	Schizophrenia	White
Nicolas	Afrikaans	Paarl	Depression	Coloured
Dorothy	Afrikaans	Kuilsrivier	Panic Disorder	Coloured
Christo	English	Woodstock	Bipolar	White
George	Afrikaans	Delft	Schizophrenia	Coloured
Chriselda	English	Rondebosch	Bipolar	Coloured
Galiel	English	Belhar	Schizophrenia	Coloured
Joanne	Afrikaans	Belhar	Bipolar	Coloured
Thalitha	English	Parow	Bipolar	White
Nomisa	IsiXhosa	Khayelitsha	Dissociative Disorder	African
Andrew	English	Woodstock	Schizophrenia& OCD	Coloured
Malixoli	IsiXhosa	Langa	Anxiety Disorder	African
Sharon	English	Vredeklouf	Schizophrenia& Depression	White

Table III depicts the participants in the study and gives an indication of the variation obtained in terms of diagnostic category, suburb, language and population group. (Pseudonyms were used to replace all names).

Additional characteristics that were incorporated in sampling decisions originated from literature. These categories were typically the variables used by quantitative researchers in their attempt to discover the possible relationships between such variables and the ability to work. Categories were also included based on a common sense expectation that such characteristics might impact on disabled people's ability, capacity or motivation to work. Tables IV, V and VI provide an overview of these characteristics.

Table IV: Participant profiles in terms of variables that might impact on work participation

		Vocational categories			
		Sheltered	Supported	Competitive	
Volunteer		Sipho	Andrew Sharon	Jessica Suzaan Donovan Nicolas George Chriselda Galiel Thalitha Malixoli	
Gender	Female	Male			
	Jessica Suzaan Dorothy Chriselda Joanne Thalitha Nomisa Sharon	Sipho Donovan Robert Nicolas Christo George Andrew Malixoli Galiel			
Diagnoses	Schizophrenia	Bipolar Disorder	Anxiety Disorders	Depression	
	Sipho George Galiel Andrew Robert Sharon	Christo Chriselda Joanne Jessica Suzaan Donovan Thalitha	Dorothy Malixoli Nomisa	Nicolas	
Illness Duration	Less than three years	Three to nine years	More than nine years		
	Sipho Donovan Nicolas Dorothy Christo George Chriselda Galiel Joanne	Andrew Malixoli	Jessica Suzaan Robert Thalitha Nomisa Sharon		

Table V: Participant profiles in terms of variables that might impact on work participation (continued)

Work history	Consistently working (Mostly stable)	Mostly working (frequent change)	Mostly not working	No work history in formal work	
	Suzaan Nicolas Dorothy Christo George Galiel Malixoli	Jessica Donovan Thalitha Andrew Chriselda	Joanne Nomisa Sharon	Sipho Robert	
Level of education	Completed Primary School George	Some High School Suzaan Sipho Andrew	Completed High School Jessica Donovan Nicolas Dorothy Nomisa	Some Additional Education Sharon	Completed Additional Education Robert Christo Chriselda Galiel Joanne Thalitha Malixoli
Support Systems (Emotional Needs)	Good support (Family, friends, church etc) Robert Galiel Donovan Malixoli Christo	Some support (Mostly family or friends) Jessica Andrew Chriselda Nicolas Suzaan Thalitha	Some support (Mostly church) Sharon Nomisa Dorothy	No support systems in place Sipho George Joanne	

The nature of support given to participants in the workplace was expected to have a major impact on the findings obtained in this study. For this reason detail is provided in Table VI.

Table VI: Participant profiles in terms of the nature of support

Support Systems (Emotional Needs)	Good support (Family, friends, church etc)	Some support (Mostly family or friends)	Some support (Mostly church)	No support systems in place
	Robert Galiel Donovan Malixoli Christo	Jessica Andrew Chriselda Nicolas Suzaan Thalitha	Sharon Nomisa Dorothy	Sipho George Joanne
Formalised work support (in work place) Andrew	External support (agency involvement) Andrew Donovan	Reasonable Accommodation Andrew Donovan	Support during illness episodes Andrew Chriselda Donovan Dorothy Galiel George	No support Jessica Malixoli Nicolas
Sharon	Sharon Sipho Robert	Sharon Suzaan	Nicolas Sharon Suzaan Thalitha Sipho Robert	Thalitha Christo Joanne Nomisa

While sampling decisions were informed by the characteristics presented above, emphasis was placed on the protection of participants' rights to refuse participation. Sampling decisions were therefore to some degree overshadowed by the process used to obtain participants; detail will follow.

4C.5.2. Negotiation of access

Locating participants

Service providers (these included occupational therapists and other professionals) that were known to assist people with psychiatric disability in the field of work were approached. The aim and purpose of the study was explained in some detail and questions that arose were answered. A request was made for the service providers to identify potential participants who, in their opinion, could contribute in the study. Service providers were asked to discuss the study with such potential participants, allowing an opportunity for initial decisions about participation to be made within the boundaries of an existing relationship. The assumption was that the power imbalance would be less pronounced between a service user and service provider who knew one another, and when the person requesting participation did not have a stake in the research. Only once potential participants had provisionally agreed to partake in the study did service providers make contact details available. I therefore did not have knowledge of potential participants who had decided not to participate. All the participants who agreed to participate were included in the study.

Obtaining consent

Potential participants were telephoned. The purpose of the first interview was explained in terms of setting up a meeting during which participants could ask questions about (a) the research project and (2) what would be required of them in terms of participation. I explained to potential participants that their agreement to participate in the study was considered provisional, and that the issue would be re-negotiated at our first meeting. Care was taken to mention that no one else (such as family member(s), employer, or service provider) would be contacted or involved in any way.

The first meeting commenced with introductions and small talk, aimed at establishing a comfortable conversation. Once a relatively easy interaction had been achieved a consent form, in the participant's home language, (see Appendices 2-4) was introduced. Time was given for the participant to read the form before reading through it together. I prompted participants to ask questions about the study at regular intervals. Participants were given the option to take time in order to consider their participation before signing the form. Two participants asked for time to take the form away with them, one to think about her participation (Joanne), the other to show his mother by way of explaining his involvement in the study (Andrew). Other participants seemed to have made the decision that they would participate in the study and were ready to start the first interview.

Context for interviews (and the issue of recording)

The best context for interviews to take place was negotiated with the participant before the first meeting (examples were home, library and work). Some guidance was given, mainly to explain that the context ideally should allow for a private conversation. The use of a tape recorder was also introduced at this time. I would have preferred not to discuss recording of interviews at this early stage, but did so to pre-empt possible discomfort at later stages. The idea was for participants to select a context in which they would feel comfortable having an interview with the intrusion of a tape recorder. However, this discussion was deliberately not concluded, instead, consent to record interviews was negotiated as a separate issue after participants had agreed to partake in the study. Two participants initially asked that the interviews not be recorded. Nomisa changed her mind three-quarters into our first interview, assuring me that she was happy for interviews to be recorded. Joanne preferred not to have the first three (of four) interviews recorded.

An attempt was made to conduct interviews in natural contexts. Three participants suggested that interviews be done in their work environments. Some suggested a meeting in their home environment. When work or home environments were not deemed suitable by participants, public spaces such as public libraries and coffee shops were used. In situations where a public library was used, I contacted the chief librarian ahead of time to ask for permission. Each time a space was made available in which the interview could be done with relative privacy and without interruption.

4C.6. Data Collection

4C.6.1. Strategies used for data construction

Narrative interviews and observation were the main strategies used in the process of data construction.

Interviewing

An average of three interviews was conducted with each participant. This was done to ensure prolonged engagement and to allow for member checking to be done. The core business of the first interview was for participants to tell their story. At the start of this interview participants were invited to relate their story of living with a psychiatric disability and work, or wanting to work. An attempt was made to identify the term participants themselves used to explain their condition. Variations included mental illness, psychiatric illness or diagnostic categories such as bipolar and depression. These terms were then used as far as possible to replace psychiatric disability when questions were asked and during subsequent interviews. Psychiatric disability was however the term used on the consent form and in explanations of the purpose of the study. A rationale for the use of this term was given as seemed necessary,

depending on participants' reaction to this label. Every attempt was made to remain sensitive to terminology used.

The second interview was arranged only once the first interview had been transcribed. Questions that emerged during transcription and initial analysis of the first interview were taken back to the second interview. The concerns during the second interview were:

- ◆ for the participant to elaborate on her story, as told in the first interview, relating particular aspects in more depth,
- ◆ questions that came to mind when the first interview was transcribed were brought to the second interview,
- ◆ any reflections or ideas that participants might have had between interviews were shared.

Most participants mentioned that they had been thinking about our conversation between interviews and offered insights, reflections or opinions that they thought might be useful.

The focus of the third interview was to do member checks. This interview was generally scheduled at least two months after the second interview. A provisional conceptual framework, developed to portray the outcome of the unfolding analysis, was discussed with participants. This framework depicted the emerging influences from all the interviews with participants but care was taken to highlight those influences that emerged from interviews with the particular participant. Ideas contained in the provisional analysis were usually confirmed and elaborated on. Participants would then pick up on the categories they might have questioned; contrasting their own views and/or experiences to explain their disagreement. Participants also used the opportunity to add more information, to explore the same issues in more depth or to share their reflections.

The pacing of interviews was done to allow at least 12 weeks between the first and last interview. This was done to ensure that I would be in a position

to recognise fluctuations in participants' health, for example shifts in mood, inconsistencies in self-presentation or changes in perception. None of the fluctuations that I identified were not already identified by the participants themselves.

Observation

Observations made were not focussed or limited according to pre-determined strategies. Observations were captured by incorporating these into transcribed interviews, constructed biographies and in reflective writing that was done as soon as possible after the interviews.

4C.6.2. The nature of data collected

Questions were designed to elicit the telling of life stories. Often during the telling of life stories participants would become reflective and introspective, sharing their story in a way that would be more in keeping with what Denzin defined as a self-story. A self story "is literally a story of and about the self in relation to an experience" (Denzin, 1989:43). It is interesting to note that the self-story is being made up as it is told. It therefore does not exist with the status of a story until it has been told for the first time; when it can then be retold as a story (Denzin, 1989). Personal experience narratives also emerged in the telling of life histories. These are different from self-stories in that the teller is not necessarily positioned centrally; their focus is on shareable experience. I found this distinction an important one. It captured very clearly the different modes of sharing during interviews. Self-stories were usually told with some emotion and with disregard of what the participant might have interpreted to be a 'good' response to give. Often participants would remark that they themselves had not before thought of an event in quite the same way. It was clear that the telling of self stories allowed for reflection and that it required the participant to foreground the self in the sharing of an

experience; something participants did not seem to do very often. Conversely, the telling of personal experience narratives seemed to have been constructed as a 'defence' against anticipated discrimination, often without challenging the stereotypes that underlie discrimination. Participants seemed to have internalised, to varying degrees, society's stereotypes about people with psychiatric disability.

Participants were not expected to tell a complete life story; instead they were asked to tell their story that was constructed around those epiphanies that related to experiences of work, no work, desire to work or ability to work.

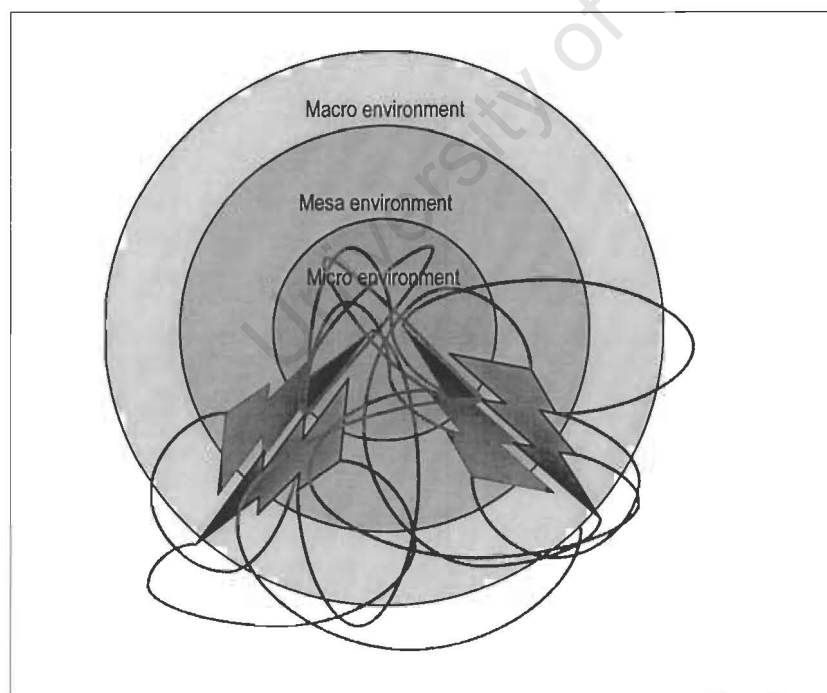
4C.6.3 Focus of data constructed at system levels

The use of interpretive biography design in this study yielded a perspective of influences that were rooted in the experiences of participants. A tendency for emphasis on influences that originate from the micro and meso environments would therefore be expected. Examples of influences that originated from micro environments would be those that were experienced on a personal level, such as reduced ability to concentrate or reduced confidence in their own abilities. Examples of influences from the meso environment would include those that originate from community level, for example work environments or family environments. During the process of interpretation, the participants' stories were situated in relation to their social contexts, thus bringing to the fore influences of meso and macro environments. Examples of influences from the macro environment would be at society level, for example social constructions that result in stigma or the policy environment that shapes opportunities. Understandings of influences from the macro environment were further enhanced through interpretive processes that were informed by existing literature. Such literature fell into one of two categories; firstly published research focussed on answering similar questions (mostly

quantitative) and secondly scholarly writings to explore pertinent concepts in depth (for example the occurrence of stigma).

The collaborative interpretive processes used in the construction of data are portrayed in Figure 1. It illustrates how participants, in the telling of their stories, placed emphasis on influences from micro environments. This was shown by a triangle-shaped arrow with the emphasis (depicted by a darker shade) on micro influences. The identical inverted shape depicts the interpretation of the participant's story within social contexts that bring into play those influences that originate from macro environments. The connecting lines show how interpretations were made across the experiences of participants.

Figure 4.1. Linking data construction with analysis and interpretation across systems



4C.7. Management of the data

4C.7.1. The production of texts

Three different types of texts were constructed to contain the data that was constructed. These were:

Transcriptions: Each interview was transcribed to create a text that aimed to best capture the narrative conversation. Prominent observations were incorporated into these texts.

Biographies: One biography was created for each participant after the first interview. Biographies were further developed after subsequent interviews and during analysis.

Reflective writing: Ideas, impressions, observations and questions that arose during interviews were captured as soon as was practical after interviews had taken place. These documents were further developed during analysis and interpretation processes.

4C.7.2. Language variations

Participants who spoke three different languages participated in the study, namely Afrikaans, English and isiXhosa.

Afrikaans: Interviews were conducted, transcribed and analysed in Afrikaans. English translations for the quotes that are cited in this report were included to facilitate understanding. (These translations were done by me.)

English: Interviews were conducted, transcribed and analysed in English.

isiXhosa: A isiXhosa-speaking occupational therapist assisted with the interviews. She took on the role of research assistant rather than interpreter. By this I mean that the interviews were conducted by both of us together. Before the first interview care was taken to explain to the research assistant

the aim and purpose, as well as the research design. The following procedure was then used during the interviews:

- ◆ I asked the question in English
- ◆ The question was translated into isiXhosa by the research assistant.
- ◆ The participant responded in isiXhosa.
- ◆ The research assistant translated the response into English.

The recorded interviews were given to another isiXhosa-speaking person to transcribe the isiXhosa sections of the interview in isiXhosa before translating it into English. I then compared the English account that had been transcribed and translated (done by the transcriber) with the English account (on audio tape) translated by the research assistant during the session. Discrepancies between the two versions were discussed with the research assistant and consensus was achieved. Very few discrepancies were found; those that did occurred when an isiXhosa concept did not have an obvious translation in the English language, hence requiring a description. For example, Siphso spoke about his community not accepting him as a *man*. This did not imply a question about his gender, but rather a denial of his adulthood; referring specifically to a particular adult status bestowed on isiXhosa males once they had undergone a traditional initiation process that involves circumcision. Only one participant (Siphso) chose to conduct interviews in isiXhosa.

4C.8. Analysis and interpretation

4C.8.1. Analysis of narrative or Paradigmatic analysis

In his explanation of analysis of narrative (or paradigmatic analysis), Polkinghorne (1995) highlighted its tendency to focus on what is common among actions. His explanation of the method included the following steps; these were followed during this project:

- ◆ Constructing (or discovering) concepts that give categorical identity to the particulars and items in the data collected.
- ◆ Examining the data for common themes and ideas.
- ◆ Inspecting the data to identify the common attributes that define them as members of a category.

This method of analysis was done once the transcribed interviews were ready. These texts were imported into a qualitative research computer programme¹⁷ to assist with the process of analysis. Each text was read to identify units of meaning that were understood to contain influences that shaped decisions or participation in work. The categories were provisionally constructed, then verified, broadened or collapsed with the reading of subsequent texts. In other words, one set of categories were developed for the influences that emerged from the texts, for example, incidents when participation in work was assisted, hindered, prevented or maintained. Participants would typically be talking about a range of issues, including:

- ◆ adapting to work,
- ◆ feelings at work and during periods of no work,
- ◆ motivations or reasons for attempting to work or deciding to stop work,
- ◆ expectations of people in their respective communities and
- ◆ anticipated and experienced difficulties.

The influences, around which categories were formed, emerged inductively from the data. The paradigmatic analysis should be understood to have been a 'first level' analysis. It stayed close to the words used by participants with limited interpretation. The first level analysis directly informed the development of themes, but was predominantly used as a mechanism to

¹⁷ Nvivo qualitative analysis programme.

ensure comprehensive coverage of all the potential influences inherent in the data.

Concurrent to the first level analysis, described above, analysis of narratives was done. I will refer to that as a 'second level' analysis and discuss it below.

4C.8.2. Narrative Analysis

A narrative analysis was the main strategy used to uncover the influences that impacted on participants' work-lives. This analysis was done through the process of constructing biographies; this could also be understood as a 'second level' analysis. The construction of biographies commenced immediately following the first interviews. The biographies were further developed, altered and refined as insights emerged during the first level analysis and after each interview. Biographies were constructed in such a way as to foreground the life plots that emerged from participants' narratives. These tended to consist of major turning point events that shaped participants' work narratives. The development of themes was therefore informed by the categories that emerged during the first and second level analyses.

It was during this stage of analysis that data was scrutinised to consider verisimilitude. Analysis was done with an attitude of scepticism. When a seeming pattern was identified in participants' behaviour or an interpretation made to reveal a possible influence, care was taken to interrogate such provisional understandings in order to develop them further.

4C.8.3. Reflexive writing for analysis and interpretation

Influences that impacted on participants' participation in work were not always communicated verbally by participants. Instead, such influences were

evident in the behaviours, decisions or emotions that were shared, for example:

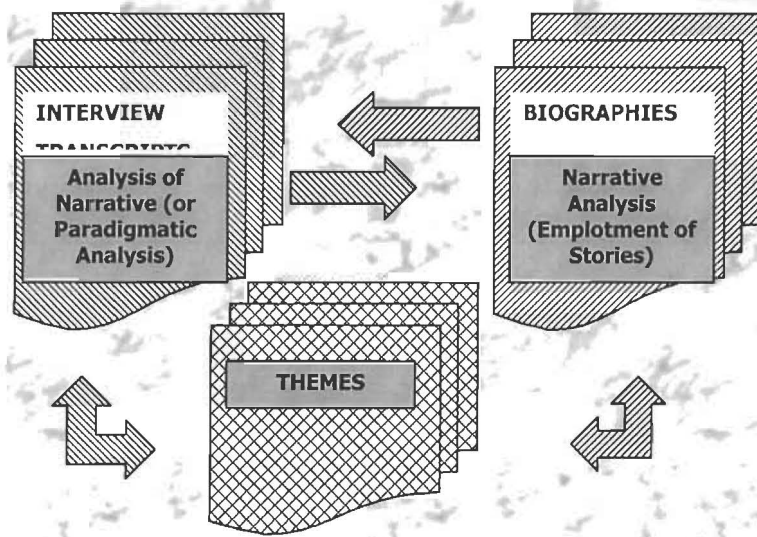
- ◆ being willing to work in contexts very different from what participants enjoyed and were trained to do,
- ◆ talking about wanting to go back to complete training but not doing anything to enrol for such training for a protracted period, or
- ◆ taking responsibility beyond what was expected. One example was when Jessica and Thalitha contacted me to give their new contact numbers when they unexpectedly moved house.

These types of influences were captured in reflective writing that was done throughout the process of data collection and analysis. Three types of reflexive writing assisted analysis and interpretation in different ways. These will now be briefly explained:

- ◆ Memo-documents in which early ideas and/or emerging trends were captured. These assisted with the recognition of trends that were similar or different between participants.
- ◆ During the construction of biographies, life plots emerged, together with epiphanies that pointed to the main influences that impacted on participants' ability to participate in work. These were captured in memos that informed the development of categories, and ultimately, themes.
- ◆ A text with the name "Who is [name] and what did I learn from him/her" was developed to record striking impressions. It captured the character and the contextual detail of relationships with participants.

These processes of analysis and interpretation were done concurrently, while interviews were being carried out. Figure 4.2. was developed to depict the way in which the two methods were combined to begin construction of an understanding of the research question.

Figure 4.2: Analysis and Interpretation



It became evident mid-way through the process of data collection that the developed categories accommodated influences from new interviews; in other words, no new categories were required to capture the influences that emerged.

4C.8.4. Participation of participants

Savin-Baden and Fisher emphasised the participation of research participants in our research processes as one of the strategies through which 'honesty' is negotiated (Savin-Baden and Fisher, 2002). I made every attempt to include participants in the process of knowledge construction. Further participation was elicited through the adapted process of member checking. Most participants engaged comfortably with the ideas presented and would relate examples from their own lives when they agreed with the categories presented. Some categories elicited in-depth discussion, either because participants found relief in the knowledge that other participants shared their experiences, or because they did not immediately identify with the category.

When participants did not identify with a category, one of the following reactions was seen:

- ◆ they saw the category as a pertinent influence but experienced it differently,
- ◆ they saw the category as a pertinent influence for other people with psychiatric disability, but did not see its applicability to themselves or,
- ◆ they disagreed with the category.

The first response led to fascinating discussions and subsequent modification of categories to incorporate these views. The third led to the participant's questioning of the category to ensure that it was in fact an influence that was experienced by other participants.

When it was time to do member checking with the first participant, I was confronted with a decision either to give feedback on the entire framework of categories, or only to give feedback on the categories that were relevant to the particular participant. I made the decision to give feedback on the entire framework, but highlighted when a category seemed relevant for the participant particularly. The main reason for this decision was that it was a less threatening way to discuss categories sensitively, because participants would not be made to feel uncomfortable. The strategy worked well and I decided to continue using it for the following reasons:

- ◆ Many participants were positively surprised that they were given the opportunity to comment on the framework of categories. Most of them verbalised their appreciation for being involved in this way.
- ◆ Most participants were truly interested to know how their views and experiences were either the same, or different, from those of other participants.
- ◆ Discussion was generated when participants were 'reminded' by the categories that they too shared similar views or experiences.
- ◆ It was a kind approach in that participants saw their own experiences in the context of a fuller picture. The impact was that difficult experiences were to some extent normalised.

- ◆ Knowledge was gained that would otherwise have been missed, for example the strong commitment of many participants to be involved with other people with psychiatric impairment and the stereotypes that participants themselves held of other people with psychiatric disability.

The member-checking interviews were tape recorded, transcribed and incorporated into the analysis in the same way as was done with other interviews. Their impact on both knowledge construction and analysis was however in some ways more significant. I believe this was because of the quality of participants' participation and the way they connected with the process of data construction.

4C.8.5. Formal analysis

The final stage of analysis involved the writing up of findings as presented in the chapters to follow. The emphasis in this phase was a synthesis of previously described processes in order to group and refine constructions of the influences that emerged. This process involved further consideration of the emphasis placed on particular aspects by considering all the available data, as well as revisiting literature.

The categories and themes that emerged from the simultaneous processes of narrative analysis and analysis of narratives generated themes and categories that will be presented in Chapters 6 and 7. The next step to consider was to show how these categories and themes were in fact impacting on the lives of participants. The focus of analysis underwent a subtle re-orientation that is difficult to capture, but that had something to do with a move away from the experiences participants had had and the influences that were currently impacting on their behaviour, towards an attempt to explicate the dynamics that resulted in such experiences and influences. The first two steps in analysis relied heavily on the experiences of each individual participant with

some of the insights generated from other participants' experiences also playing a role; it was, however, for the most part dominated by the intra-case analysis. The third step in analysis, namely formal analysis, was constructed on a global view of influences that emerged across the experiences of participants. This analysis was therefore predominantly inter-case in focus.

It was during the formal stage of analysis that attention was given to politics as a mechanism to legitimise the research done. It is here that the marginalisation of people with psychiatric disability had to be considered. Participants' own endeavours to make sense of the influences that impacted on their participation in work had to be considered within a macro context in which the social constructions of such disability would be considered.

Conclusion

The methodology that was presented was well suited for use with the participants in the study and for finding answers to the research questions. Its participative character allowed for construction of findings that were based on more than one dimension. Participants shared their views and experiences, for which their life stories provided a context and an understanding of the temporal dimension. Processes of analysis and interpretation were enriched by understandings gleaned from the matches and mismatches between participants' 'telling a life' and their 'living a life' dimensions. The findings are presented in the next two chapters.

Chapter 5: STEREOTYPES AND STORIES

Introduction

The main purpose of this chapter is to introduce the participants in this study and to show how their lives challenged many negative stereotypes held by society and by some health professionals. Participants' stories were shared during the interviews, but these stories were also being lived day by day. The depth of participants' experiences and their open sharing of their stories in themselves made me aware of a world that stood in complete contrast to the types of stories that usually dominate service settings and revolve around illness. The humour, seriousness, compassion, sorrow, sincerity and detail with which participants told their stories foregrounded full lives in which psychiatric impairment was one (albeit an important) influence alongside many other influences that their authors generally fully appreciated. Rich lives characterised by many different aspects served to contextualise episodes of hospitalisation as small and contained (albeit usually extremely traumatic) events that were flanked by many regular and diverse experiences. The tendency in medical model service settings has been to focus on people's symptoms and on behaviours associated with psychiatric impairment to the neglect of broader issues such as strengths, life circumstances, values or their hopes for the future. The extent to which such a tendency had 'reduced' or 'stripped' people of their contextually rich lives was highlighted by the contrast of meeting participants in their own environment, on their own terms and without any expectation that they be required to fit a particular mould in order to be judged 'sane'.

Participants' stories went against many stereotypes about people with psychiatric disability. Negative stereotypes often are not recognised for what they are and therefore go unchallenged. In this chapter a number of such stereotypes will be shown to be untrue as the life stories of participants

illustrate a reality opposite to that which shapes dominant stereotypes. Many health professionals do not have a conscious awareness of the stereotypes that influence their decisions and actions pertaining to people with psychiatric disability. Negative stereotypes are most noticeable as stigma, as was discussed in the preceding chapters. Stigma is seldom expressed as an active rejection of a psychiatrically disabled person. Instead it presents as an all pervasive passive acceptance of the exclusion of people with psychiatric disability from participation in important social domains. Work is one such domain. The stereotypes introduced in this chapter were understood to be interfering with the conceptualisation of people with psychiatric disability as workers – they were based on my own experience.

5.1. Stereotypes about people with psychiatric disability and work

During more than two decades of work experience in various psychiatry service settings I developed an appreciation of the attitudinal barriers that people with psychiatric disability face from day to day. Prominent stories were those that contained instances of abandonment, abuse, neglect or ridicule. Examples included families who refused to accept patients home after discharge or patients being ridiculed by community members who would call out names such as 'malletjie'¹⁸. These types of behaviour were often the result of stigma attached to psychiatric impairment. It also relates to an inability to separate the person, from the impact of her impairment; which means that judgements are made about behaviour over which the person with the impairment might not have had control. The damaging consequences of such episodes are obvious and open; different from more subtle, broadly held beliefs and stereotypes that I believe to be equally damaging. In fact, I hold the view that explicit instances of prejudice are easier to obfuscate, because these are easily identified. When negative stereotypes are

¹⁸ An abusive term, literally "small crazy one", from Afrikaans *mal* - 'mad/crazy'.

operationalised without these being made explicit, the consequences are usually not discerned; ultimately resulting in attitudinal barriers that are not challenged. My own awareness of social stigma associated with psychiatric disability has been confirmed by published research (Camp et al., 2002; Perlick et al., 2001; Penn and Corrigan, 2002; Sirey et al., 2001) and social commentary (Herrman, 2001; Johnstone, 2001; Kaas, 2001). However, the stereotypes presented in this chapter are the ones that in my own experience were foremost when it comes to hindering people with psychiatric disability in their ability to work. The recurring stereotypes are presented in inverted commas and discussed below (5.1.1.–5.1.10).

5.1.1. "People with residual symptomatology cannot work"

During the years I worked in the field of psychiatry the view was held that people who are experiencing residual symptoms associated with psychiatric impairments were not well enough to work. In fact, it was feared that working at this stage could be detrimental because of the associated stress.

Both Sharon and Andrew had been experiencing overt symptoms of schizophrenia for more than a decade. Yet, both of them were working at the time of the interviews. Both participants experienced positive and negative symptoms, but they themselves were most affected by positive symptoms, particularly verbal hallucinations.

Andrew worked as a security man and general assistant at a home for older people. He used a 'Walkman' to block out the voices that he heard whenever he was alone. Andrew also experienced symptoms associated with an obsessive compulsive disorder (OCD). This was a more recent problem, which added to the strategies he needed to control the impact of psychiatric impairment on his life and on his work. Accommodation was made at work when symptoms associated with OCD made it difficult for Andrew to perform

some of his work tasks, for example he was no longer expected to assist with washing the residents. This accommodation was crucial; without it Andrew might not have been able to continue working. It should be noted that the director of the home, a social worker, also happened to be Andrew's mother. The accommodation made was however in line with the guidelines of the Code of Good Practice (Department of Labour, 2001). Andrew never completed school and he was not able to work for more than a week in any of the entry-level jobs he attempted. This all changed when he started to attend Roseberry House¹⁹ and was placed in the Transitional Employment Programme (TEP). Through his involvement in the TEP Andrew began to trust his ability to participate in work. He was encouraged by the support of other members, particularly staff members and found great comfort in the knowledge that someone else would be available to do his job when he was not. He relied heavily on messages from other members that they thought he would succeed and felt he could ask them to explain things he did not understand. Andrew improved his own performance as a worker whilst in the TEP and was assisted to negotiate for his current job by staff members of the TEP.

Sharon had been at university for one month, having won a scholarship to study English literature, when she first became ill. After her first hospitalisation she made one more unsuccessful attempt to study before finding work that she was able to maintain for just over a year. Sharon was then unemployed for 13 years, until she obtained administrative work in a library as part of a supported employment programme. Since starting to work, Sharon carefully monitors her daily activities in order to prevent exhaustion which leads to intrusive hallucinations that she experiences when over-tired. Sharon has been working reduced hours; four hours per day for four days a

¹⁹ Actual name of the organisation was changed. It is a disabled people's organisation that functions on the principles of a clubhouse as described in Fountain House New York City (1999) *The Wellspring of the Clubhouse Model for Social and Vocational Adjustment of Persons with Serious Mental Illness*, *Psychiatric Services*, **50**, 1473-76.

week. As she described her current work, a range of emotions were palpable. Sharon saw her work as a valued opportunity, she enjoyed the contact with her co-workers and she loved being surrounded by books. Sharon explained how her current work situation resembled the dreams she initially had for her future after leaving school. Work had a major positive impact on her identity and gave her new hope for the future.

Not only did participants continue to work while they experienced symptoms, but some even found that the benefit of work assisted in the alleviation of the symptoms they were experiencing.

Christo had worked as a site surveyor for seven years and had been promoted to site supervisor one year before his first experience of bipolar mood disorder. During his first (undiagnosed) manic episode Christo resigned from his job because he was planning to start his own business; shortly after this he was hospitalised for the first time. Immediately following discharge Christo unsuccessfully tried to negotiate with his employers to return to work and because more than three months had elapsed after he resigned he could no longer approach the Commission for Conflict, Mediation and Arbitration (CCMA). Christo was unemployed and started to receive bills for the debts he incurred during the time he was experiencing mania. The expensive furniture and technological equipment he bought had been stolen from his house during hospitalisation; apparently by a stranger he had invited to live with him at the time. Christo bravely faced the devastation caused by his own doing, not finding much solace in the fact that his judgement had been impaired by illness. He took the first opportunity he could find to work, even though this meant he had to do manual labour. When our first interview took place, one year after he had been discharged from hospital, he had moved on to a better paid job as a general handyman. By the second interview, Christo had been made redundant and he once again focussed all his energy and efforts on finding work. During this interview he highlighted the negative effects of not having work, directly linking such times with increased symptoms of

depression. When he later started to work with street children on the streets of Cape Town, he marvelled at the positive impact his work was having on the alleviation of his depressive symptoms.

Andrew, Sharon and Christo were not the only participants who were able to work successfully and have a sense of recovery while also experiencing symptoms; many other participants maintained their work whilst experiencing some symptoms. It should however be noted that the symptoms experienced were either residual symptoms or affective symptoms, particularly depression and hypomania. These are symptoms that participants would have had time to get used to and that they felt were now more or less in their control.

5.1.2. "People with psychiatric disability do not want to work"

Low internal motivation is often cited as a reason why people with psychiatric disability do not work. It has been my experience that this explanation is often used to overrule reasons people themselves give for not finding work or not maintaining work. It is to some extent linked with an attitude that disabled people should be grateful to be given for any opportunity to work; no matter what their personal preference might be.

Reduced motivation is indeed a powerful symptom associated with particular psychiatric impairments. It should, however, not be used to over-simplify and label the difficulties experienced by people with psychiatric disability. All of the participants interviewed in this study wanted to work. Times of no-work were associated with hardship and frustration. Participants did experience difficulties at work, not unlike people without psychiatric disability, and complained about aspects of work, as most people do. This did not indicate an intention or desire not to work. During interviews with participants who did not have work, their need to work was emphasised to such a degree that it might be have been considered a preoccupation. Such a preoccupation

translated, for some, into ongoing attempts to seek work. Other participants, seemingly less confident that work could be a reality in their lives, did not seem to take as much action. Participants who worked concerned themselves with doing well in order to ensure maintained involvement at work. More than one participant shared the opinion that they had to do better than non-disabled co-workers as proof of their worth.

For example Suzaan was based in the head office of a large liquor distribution company. She started her career in this organisation as a cashier after dropping out of school. Suzaan later explained that she left school because of an unplanned pregnancy; something she never regretted but that came during her first experiences of being hypomanic. At the time of our first interview, Suzaan had been working for the same company for 23 years. Suzaan lived with bipolar mood disorder and experienced heavy and prolonged bouts of depression following frequent manic episodes that would lead to hospitalisation. Since late adolescence, hospitalisation was an almost annual occurrence, with the exception of three or four years. Suzaan had had many periods of absence from work and had used more than the allocated amount of sick leave. She explained that going to work was the reason she got up on days that she did not feel she had the strength to leave her bed. Suzaan told me that she would be discharged from hospital on a Friday and be back at work on the Monday. During the second interview Suzaan jokingly said that she hoped to marry a rich husband who would take care of her, thereby allowing her not to have to work. Suzaan was feeling 'low' at the time and was finding it difficult to get up for work and to get going. She was working flexi-time (started later but was still doing a full day) to accommodate the slow start in the morning. Suzaan's 'joke' led me to reflect on her motivation to work and helped me to understand the toll Suzaan's illness was taking. It would be fair to say that she required a high level of internal motivation to keep going during stages of intense depression when she was consistently feeling 'low'. Work was in fact an important and integral

part of Suzaan's life. She seemed to sense that without work, her life would come undone.

The toll of some types of psychiatric impairment on endurance should not be underestimated. Certain (differing) aspects associated with work, for example socialisation or getting instructions in the presence of co-workers could be intensely stressful. Some participants did have frequent periods of absence from work. Labelling periods of absence from work as 'lack of motivation', without sufficient scrutiny to determine the cause of such an absence, would however be a dangerous oversimplification.

Robert, who had been a high achiever at school (was head boy and played sport at provincial level), first experienced symptoms associated with schizophrenia in his final year of studies for a LLB qualification²⁰. He obtained his law degree the previous year and was one week away from writing his final examinations when it became apparent that he seemed to have been experiencing a prodromal phase of schizophrenia all through his final year. Although he only needed to be hospitalised twice for short periods of time, he worked for no longer than a few weeks in fourteen years. Robert had however continued to play tennis competitively at a club in his neighbourhood. Robert had made an active decision not to join the TEP offered by Roseberry House where he attended daily and he was not attempting to find work. Robert repeatedly emphasised the goals he set for himself while at Roseberry House. These goals were not very ambitious and were very long term objectives. For example, his goal for one year was to learn to use one software package (Powerpoint) and to teach other members at the Clubhouse the use of another (Excel). Robert spent, on average, six hours daily at Roseberry House where he was given the most responsible tasks (bookkeeping and banking) and was involved in 'teaching' other members, without any remuneration. Robert's explanation of the decision not

²⁰ A postgraduate law qualification that is a required qualification for all advocates.

to work hinged on his view that he was recuperating and getting back the skills and abilities that he had lost, and that he was set on completing his LLB before attempting work. Robert admitted openly that he did not wish to re-enter the world of work as somebody with reduced status; this might have had something to do with the fact that he did not have to earn money in order to live comfortably (his parents was taking care of his financial needs). Robert might be labelled as 'lacking internal motivation' and therefore not wanting to work. I believe such an assessment would be an oversimplification of the influences at play. A disproportionately large fear of failure was very evident in Robert's narrative, as well as cues that suggested that his family preferred the low-risk lifestyle he chose. As time went by, Robert recognised the accumulation of non-productive time that he would have to account for when he did look for work. The future picture that Robert had been working towards before first becoming ill was one he could not let go. He seemed to be casting himself into the role of someone needing to work hard to recover from a temporary (and devastating) experience and that once this had been achieved, he would resume the life he had always planned to live. Entry into the TEP or starting other work would mean that Robert would have to accept the fact that he had a reduced capacity to work and that he would not achieve the goals he had set for himself. His family similarly seemed more happy with their son focussing on recovery and prevention of future relapse, and less happy for him to start an entry-level job of much lower status than the one they always envisaged he would have.

5.1.3. "People with psychiatric disability are too low functioning for the open labour market"

A very broad-based belief is that work in the open labour market (OLM) is only suited to high functioning people and that most people with psychiatric disability are too low functioning to work in the OLM. This notion is problematic from two perspectives; firstly people with psychiatric disabilities

are found to participate in a broad range of work categories and across performance levels and secondly, the OLM offers jobs which require skills from the most basic to the most sophisticated, and across many categories.

A further concern is the tendency to describe people as high or low functioning without measuring performance at work. This is poor practice. Yet, this descriptor of performance is often used to classify people with psychiatric disability. Low functioning is generally taken to mean that the person could not be expected to perform social roles, such as work, successfully. Indicators used to determine when people are low functioning could include the severity of symptoms associated with a chronic psychiatric condition or intellectual impairment. Level of education would usually be used as an indicator, as well as the level of insight demonstrated. Some of these variables were illustrated to have poor predictive value when it came to ability to work. When a vague classification such as 'low functioning' informs decisions made about the opportunities that people are given, it is likely to have detrimental consequences.

George would have been considered 'low functioning'. He spoke a dialect of Afrikaans (Kaaps) but his speech was slurred and his conversation often lacked coherence. He did not have insight into the experiences associated with paranoid schizophrenia with which he had been diagnosed. Instead he believed that he was being persecuted and harassed by youngsters who meant to harm him, but only during those times when he was ill. He had not sufficiently understood his impairment to recognise when he was in fact experiencing paranoid symptoms.

George had been working for the same company for 17 years. He arrived at work every day to find a loaded truck ready for him and two other men to deliver dairy products to supermarket chain stores. He started work early, at 06h00, but finished when all the deliveries were done. He worked for six days of the week and had to be up by 04h30 to start work on time. George spoke

about his job with fondness. It was obvious that the demands of the job were well within his abilities and that the freedom associated with it suited him well. He seemed to enjoy the camaraderie that he shared with his co-workers. The work routine was always the same. He spoke about the work being more demanding on Fridays and Saturdays and towards the end of the year when more stock was requested by the shops they served. This meant they had to work a bit harder, but George felt he could cope with the increased demand during those times.

George's story contradicts both of the assumptions embedded in this stereotype. The label 'low functioning' is shown up to be flawed. George owned the modest home in which he has been living with his large family. He spoke about his children and was proud that he was providing them with a good education and opportunities to have a better life than the one he has had. His long career illustrates that the open labour market (OLM) comprises many categories of work, all requiring different levels of performance. Thus, the OLM market offers opportunities to people in a vast number of occupational categories which varies in terms of performance requirements.

5.1.4. "Problems at work are ascribed to the psychiatric impairment"

There is a tendency to assign problem behaviour that occurs in the workplace on the person having a psychiatric impairment. Participants all had stories to tell in which they felt stereotypes were used in this way. They would meet the demands of their jobs to a greater or lesser extent; however, it seems that when psychiatric disability comes into play, problems associated with work performance tend to be ascribed to the person's psychiatric impairment.

Thalitha was working part-time as a music teacher at a primary school, did voice instruction at a university, was the organist and musical director in her church and when the opportunity presented itself, would perform musicals or

opera on stage. Thalitha was sharing her work history when she told the story of having been 'fired' from one of the schools where she had worked. Thalitha was playing the piano and assisting another teacher who was directing the school choir when she found herself in a situation in which the learners were misbehaving and being rude. She called them to order by hitting a stick on a table and, when they were quiet, she reprimanded them. Thalitha's contract with the school was terminated, the reason given was that she scared the children. Thalitha had not disclosed the fact that she was living with a psychiatric disability during her job interview. However, soon after starting her new job she disclosed to co-workers. Thalitha believed that senior people at the school came to regret her appointment when they became aware of her disability status. She therefore did not accept the reason given for her dismissal and believed that she was asked to leave because of her psychiatric impairment.

5.1.5. "People with specialist knowledge are needed to assist"

Potential employers often will not consider employing people with psychiatric disabilities because they believe themselves to be ill-equipped to understand the needs of psychiatrically disabled people. Many participants' stories contradicted such a belief and illustrated how beneficial the input of employers and co-workers could be. Galiel was one such a participant.

Galiel completed school before he started work as a storeman. During this time he enrolled for a part-time course and qualified as a fitter and turner. When Galiel first became ill, he became suspicious of his co-workers, causing some disruption at work. His employer and co-workers knew him well and realised something was wrong. Galiel's employer's sensitivity towards his needs was the main reason why he could continue to make a valuable contribution to the company. He liaised with Galiel's wife, assuring the family that Galiel's job would be safe. This was done at the onset of Galiel's illness

when his prognosis was not at all clear. Galiel emphasised the importance of knowing that his job was safe; this provided him with the impetus to get better. Galiel returned to work after one month at home, even though he was not yet able to cope with the demands of his job. He was given a further three months of sick leave although he was entitled to only one week. He started working half-days, gradually increasing his work hours. Galiel was quietly proud of the fact that he was doing even better at work than he did before his illness. His explanation was that he channelled the gratitude he felt towards his employer into his work, thereby improving his accuracy and production speed.

It is not realistic to expect that all employers would go to such lengths to accommodate their workers. It was however not an isolated occurrence. Nicolas had experiences of both a very accommodating employer and one that was discriminatory. Nicolas worked for a wholesaler for seven years and had been promoted into a senior position shortly before his first admission for the treatment of depression following a suicide attempt. After a second admission, which followed shortly after the first admission, he was pressurised by his manager to resign. Nicolas remained unemployed for one and a half years before he obtained the job that he still held at the time he participated in the study. He worked in a medium-sized supermarket and was expected to stock shelves, do some cleaning and also to collate orders. Nicolas had a very supportive employer; not only did he allow Nicolas to take time away from work in order to go to the clinic, he also assisted by giving advice and reminding Nicolas to take his medication.

In these examples, and others, the employers were instrumental in promoting, maintaining or hindering work participation. These employers furthermore understood the needs of their employees and how to assist them.

5.1.6. "People with psychiatric disability are not the best workers"

Even those who believe that psychiatrically disabled people are able to participate in work will seldom expect that they will be excellent at work. Such a tendency is unjust and could limit work opportunities and negatively affect promotion. It is based on the same types of stereotypes explained above.

Both Nicolas and Galiel were excellent workers. Galiel's precision work could not be done by other employees. Although Nicolas seemed to fret about his performance, his employer seemed to be more than satisfied with his work. On completion of our second interview, on Nicolas's off-duty day, he returned to work to clean the floor. He explained that he had attempted, at the employer's request, to train other employees to take over this task. Neither Nicolas, nor his employer, was satisfied with the quality of their work and each time the task would be given back to him. Nicolas was now cleaning the floor outside his normal shifts, receiving extra remuneration for the additional hours of work. Nicolas, a person with psychiatric disability, demonstrated that he excelled at work.

5.1.7. "Knowledge of psychiatric disability will lead to rejection"

Most participants in the study seemed to have internalised this view, a view which it would seem is held by many health professionals and members of society. Chriselda and Christo, as well as Nomisa, had experienced discrimination as a result of their psychiatric impairment becoming known. They drew links between lack of promotion or lost work and the fact that their direct supervisors or employers had knowledge of them having a psychiatric impairment. Some participants made the decision not to disclose for fear of being discriminated against. The experiences of other participants illustrated that employers and co-workers did not discriminate, rather, they accommodated and assisted participants. Galiel and Nicolas' stories, shared

above, are good examples. The stories of Andrew and Sharon illustrated that it was only after disclosure of their disability status that they were able to find work.

5.1.8. "People with psychiatric disability always need special accommodation"

Malixoli lived with an anxiety disorder and had always felt shy and lacking in confidence. When he reached adolescence, his anxiety became linked to social situations and, more specifically, exposure to women. Malixoli lived with his mother in one of the informal settlements on the outskirts of Cape Town. He was enrolled for his masters degree, at the same time as working for the university. He also developed his own business, spending time after work hours to design, make and sell clothes for his friends and other customers. Malixoli was able to deal with his anxiety when he was doing business. He explained that he learnt to 'talk business' to his friends; even when he found himself in social situations. He explained that 'business talk' allowed him to play to his strengths, the confidence he experienced related to the success he had in business dealings. This seemingly insignificant change helped greatly to deal with his shyness and the associated feelings of anxiety. Work itself, for Malixoli, provided the containment and focus that enabled him to deal with his anxiety. He was substituting leisure occupations with work occupations and relied on the same elements that he applied in business to manage social situations. For example, he relied on predetermined structure to reduce his anxiety. He functioned well within a predictable structure. In preparation for our first interview he phoned to ask what would be expected of him and how long it would take. When I explained that a pre-determined interview guide would not be used, he suggested that the interview last for 45 minutes. He phoned to confirm that the meeting was happening 30 minutes ahead of time and arrived early. The structure he brought to an anxiety provoking situation helped him to contain his anxiety.

The level of demand required by Malixoli's combination of work-related tasks is the opposite of what one would expect of somebody with an anxiety disorder. Malixoli's story challenged the stereotype that people with psychiatric impairment always need help from others.

5.1.9. "Psychiatric disability increases hardship and brings negative consequences"

There is an automatic assumption that the occurrence of psychiatric disability brings hardship and will necessarily lead to negative consequences. Two participants experienced the opposite.

Nomisa's story was different from that of the other participants. Her illness brought some relief from a life of hardship. Having a psychiatric impairment brought suffering, but also provided a form of escape at times of severe hardship and turmoil. In the long term, it provided a very modest but stable source of income in the form of a disability grant.

Nomisa's life story highlighted the trials and tribulations faced by many black women who have lived most of their adult lives under *apartheid* in South Africa. Nomisa was trapped, unable to live her dreams as an expression of her potential. She wanted an education in order to become a nurse or a teacher. This desire lured her into marrying a man who promised that he would pay tuition for her to complete her schooling, something her parents were unable to do. Once married, she was soon pregnant with the first of her five children. Her dreams of an education never materialised, leaving her in a situation of powerlessness.

Nomisa first became ill when her husband brought a new woman to their home to take her place as his wife. He wanted Nomisa to maintain the

household and continue to care for their children. Nomisa's sister removed her from the situation and invited her to live in Cape Town. She had to find work and make a life for herself. Nomisa found part-time work as a domestic worker, but spent most of her time without employment. With her disability grant (DG), she has been able to significantly improve the quality of her life. Having money, in the form of a DG, was not the only improvement that came along with the impairment. Benefits were not only financial. Nomisa joined a wellness group that brought a sense of purpose and some recognition. Nomisa became the natural leader of the wellness group. She found a meaningful place for herself in the group and in her community.

Similar to Nomisa, Dorothy also experienced some positive outcomes associated with having a psychiatric impairment. It brought a way out of a very restrictive environment. Dorothy lived with her mother in a settlement that was given the name "Smarty Town" by the locals. She shared a tiny house with her mother and three brothers. Dorothy had a daughter who was born when she was a schoolgirl aged 17 (Grade 12). After the birth of her daughter, she returned to school to complete her high school education; her mother took care of the baby. Directly after completing her schooling, Dorothy started to work in a large chain grocery store. She started as a casual worker but was later made a permanent member of staff. Dorothy had moved out of her family home and was happily living with her daughter when her father died and she had to move back home to look after the family. Only one other member of the family, her brother, worked; the family therefore relied on Dorothy to pay the bills.

Dorothy was hospitalised for an affective disorder with psychotic features. She started our first interview by telling me that she had learnt a valuable lesson; "to speak what is on [her] mind and to ask for help if needed". I was surprised when Dorothy told me that she thought she needed the breakdown and subsequent hospitalisation the previous year. I clarified the point with her, asking her directly what she meant by her words "I think I needed it".

She explained that she needed the breakdown because it changed her outlook and taught her to take better care of her own needs. Her illness brought with it a sense that "the worst has happened". The long term consequence was that she experienced the freedom she needed to be assertive, despite immense family pressure. Having a psychiatric impairment meant that she had to look after herself and it brought a realisation that she had to consider what was good for her. She was planning to move out of the family home and to continue her relationship with a man of whom her mother disapproved. Dorothy believed she would not have come to these realisations if she had not experienced the psychiatric impairment.

5.1.10. "People with psychiatric disability need help, support and guidance rather than providing it"

Throughout the study it was evident that many participants were in fact able to provide support and guidance for others. For example;

- ◆ Nomisa took a leadership role in the wellness group she belonged to. She also took the initiative when it came to arranging funerals or other significant community events.
- ◆ Dorothy was the only person in her family who earned an income and who could be relied upon.
- ◆ Siphso worked as a member of an entrepreneurship group in Khayelitsha where he took a leadership role.

Most participants spoke often about helping others with similar problems. Different variations of 'giving back' to those in need was a strong theme of their stories. Their capacity for empathy and a shared understanding of what life could be like when they were at their worst seemed to enhance their interest and capacity to want to alleviate the suffering of others.

Conclusion

Participants' narratives painted a picture that did not fit into the many stereotypes that are often held about people with psychiatric impairments. However, participants were all deeply affected by the impact of psychiatric impairment on their lives. Their decisions about work, and other life domains, were shaped by the immediate effect of psychiatric impairment and by the strategies they employed (some more consciously than others) to normalise their lives as far as possible. A detailed exploration of the impact of psychiatric impairment on the lives of participants and the strategies they employed to counteract these will be discussed in the next chapter.

University of Cape Town

Chapter 6: LIVING WITH DIFFERENCE

Introduction

This chapter will focus on the approaches used by participants to deal with difference and with the possibility of relapse. It will explore the adaptations that participants made in their life-spaces. By life-space I mean 'those natural contexts in which people regularly participated in occupations'. The themes presented represent those influences that shaped decisions about participation in general but with a specific focus on work. These are *integration of competing identities, strategies for healthy living, approaching life differently, identity rebuilding strategies* and *managing stigma, ignorance and prejudice*. The impact of these themes on participation in occupations, particularly work occupations, will be considered.

6.1. Integrating Competing Identities

Potentially competing elements that were shown to influence the construction of identity were identified. These are diminished by impairment, identity defined by others, illness identity versus worker identity, construction around being a helper versus the one needing help and also competing health beliefs. Trends in participants' lives suggested that the benefit gained from resolving potential conflicts between competing elements of identity improved their ability to participate in work.

6.1.1. *Diminished by impairment*

Participants highlighted the injurious effects their psychiatric impairment had on their sense of identity. These were closely associated with negative symptoms they experienced, examples include;

- ◆ mood swings that reduced experiences of joy and happiness,
- ◆ impaired judgement that left them with financial debts and experiences that were generally embarrassing,
- ◆ impaired problem-solving that led to decisions that they later came to regret,
- ◆ hallucinations or delusions that brought confusion and fear,
- ◆ ideas of persecution that led to broken relationships.

Changes to identity were most noticeable when participants first experienced psychiatric impairment; prominent negative consequences were also brought with relapse. However, participants also noted lasting residual effects such as reduced ability to concentrate. These lasting negative effects were most feared because these had a lasting impact on identity, for example most participants experienced themselves as less confident and having reduced self-esteem.

Often when participants did not experience symptoms they would be reminded by family, friends or co-workers who thought (incorrectly) that participants' behaviour or feelings were affected by symptomatology. This caused irritation and anger in participants who felt that they were not trusted and who did not want to be reminded of 'bad' experiences during relapse. Whilst the irritation associated with such events had a short term impact, participants were left with the message that they were not trusted to have the insight required to identify and to manage the symptoms of their illness. When participants had a history of not being able to recognise symptoms and relapse, these events would have an even bigger impact.

The important consideration is that symptoms could cause feelings of shame, beliefs of weakness and of being less worthy than 'normal' people. Here Chriselda is talking about returning to work to face colleagues who saw her when she first experienced a bipolar mood disorder whilst at work. The humiliation she experienced was clearly evident.

"And .. the sort of uhh.. [deep sigh] my having to fax letters and to send my .. my sick certificate, hospitalisation certificate to companies and sort of the 'Oh gosh, these people are going to go' "Ag shame.. she just came from [Name of psychiatric hospital], she must be off her rocker!" And .. the sort of.. stigma that is attached. The first couple of weeks, it was.. everybody was- that knew me.. and .. those that saw me in hospital, when I was.. drugged out of my skull.. and was deranged and really loony.. and .. they were handling me with kid gloves, which I understand.. because they were not sure if I'm on or if I'm off" [starting to cry again]. [Chriselda]

Thalitha was one of the two participants who contested the idea of being diminished by having a psychiatric impairment. This contrasted with the other participants who all felt that because of having a psychiatric impairment they experienced diminished worth and reduced confidence or ability. It should however be noted that the intensity of these feelings varied greatly from one participant to the next. Thalitha insisted during the final interview (in which member checking was done) that having a bipolar mood disorder was a part of who she was in much the same way as other aspects of her personality formed a part of who she was. The excerpt below was taken from this discussion:

"But you see to me, .. spoiled.. not a spoiled identity. That is me .. The 'after' is more just sort of in fact, not reducing self worth, but um.. .. learning to value one's worth even more. .. Not reducing it. [Long pause]. Um ..with me, it's not a reduction or an impairment, as you said the before and the after. The after, .. isn't after, it's .. learning to really take made aware of ones worth, .. and being forced .. to .. change one's life in such a way that .. because for me I feel, that when I have the um.. episodes, it's been I work too much..." [Thalitha]

Thalitha explained this view by explaining the positive associations that were being made about people with bipolar mood disorder in some countries. As

early as our first interview she explained that, for performers, having a bipolar mood disorder could be regarded as a positive attribute and added her views indicating her agreement. It should be clarified that Thalitha's life had been negatively affected by psychiatric impairment. She did not work full days because she consciously monitored her levels of fatigue. This severely limited full-time employment opportunities that offered benefits such as pension or leave; which placed her in a financially vulnerable position. Thalitha's work commitments comprised;

- ◆ voice instruction for a number of students at a university,
- ◆ part-time music instruction at a primary school where she also rehearsed and conducted the choir for each class
- ◆ organist at her church where she also conducted the choir and would oversee rehearsals once a week, and
- ◆ piano tuition at her home.

Although Thalitha was not performing during the time our interviews were done, she usually accepted work as a singer on stage at least once a year.

The contrast of Thalitha's perceptions with that of other participants led to an understanding that the impact of psychiatric impairment on identity can be more damaging, or less damaging, depending on the processes of identity construction. Firstly, Thalitha did not perceive the social context in which she performed to be hostile; this might have reduced the negativity of influences that impacted on her identity. Secondly, the impact of symptomatology on identity was seen to be enhancing those characteristics she valued, rather than reducing them. The dynamic interplay of influences that informed her construction of identity might have led to the fact that she did not experience the impairment as having had a devastating effect, when compared with other participants.

6.1.2. Identity defined by others

Participants seemed to rely on the judgement of others when they were gauging how well they were doing, the value of their own contributions and their acceptability as participants within the work place. It should be noted that this tendency seemed to apply beyond the work setting, to family situations as well. Criticism from others would have a detrimental impact on participants' own judgement of their acceptability or their contribution. Participants did not always accept criticism at face value, but would nonetheless spend considerable time thinking about such judgements. Evidence that contradicted such criticisms would be put forward and revisited by participants in an attempt to refute what they considered unfair criticism. On the other hand, positive feedback or behaviour from others affirming the role and place of participants were found to be greatly encouraging. Participants would often repeat statements made by others to affirm their own contribution and worth. Similarly, they would scrutinise the behaviour of others around them for signs of empathy. When co-workers or family gave some indication that they appreciated the difficulties confronted by participants, or that they recognised participants' attempts at overcoming obstacles, participants read validation into this.

Nicolas' interpretation of other's behaviour towards him was influenced by his own previously held negative views regarding people with psychiatric impairment. These views were developed during a childhood that was characterised by extreme poverty and entrenched patterns of alcohol dependence that characterised the daily lives of his family members. Nicolas, the youngest of twelve children, was the only one who did not use alcohol, something he came to associate with psychiatric impairment. Although Nicolas altered his views of people with psychiatric impairment after he first received treatment for depression, he continued to expect other people to have negative views that were similar to those he himself had held. This resulted in

his withdrawal from his friends and unhappiness with the community in which he grew up in since his birth:

"Ek wil 'n ander heenkome gaan vind.. want ek vind uit.. vanwee my siektetoestand, almal wat ek ken, hulle behandel my nie.. soos hulle my eers behandel het nie. En ek kan dit nie hanteer nie.. dit kan ek nie hanteer nie. En ek dink nie dis reg van hulle om so te verander nie. [Small pause]. Ander tye was ons in 'n klub gewees, 'n snoeker-klub, waarvan ek die kaptein was. Toe ek in die hospitaal beland, toe vat hulle my kapteinskap af.. ek is nie meer kaptein nie.. ek is nie meer in die senior span nie.. ek is na die junior span geskuif. Toe vra ek nou waarom.. dan het hulle met my suster gaan praat, my suster het my siektetoestand aan hulle verduidelik.. toe sê hulle hulle wil nie meer daardie druk op my plaas nie.. van te presteer nie. Toe sê ek maar.. dis nie nog druk nie, dis dan ontspanning vir my. Hulle sê nee, in 'n kompetisie is dit nie ontspanning nie, om kompetisie te wen, sit ekstra druk op jou. In die juniorspan.. is dit nie so nodig nie. Dis maar net 'n oefenspan, as't ware, wat na die A-span toe gaan. Toe sê ek maar dan is dit mos nutteloos vir my, en toe onttrek ek my uit die klub uit want.. ek voel ek is goed genoeg vir die A-span. Hoekom moet ek na die B-span toe gaan? Toe sê ek nee, ek stel nie belang meer nie". [Nicolas]

I want to find another home for myself.. because I am discovering.. that people are treating me differently due to my illness, everybody who knows me treat me differently.. different from the way they used to treat me. I don't think it is fair of them to change in this way [small pause]. I used to belong to a club, a pool-club, I was the captain. When I landed up in hospital, they took my captaincy away.. I am no longer the captain.. I am no longer in the senior team.. I was moved to the junior team. When I asked about this.. they told me they went to speak to my sister, she explained my illness to them.. so they said they did not want to put pressure on me.. to have to perform. I told them I did not experience pressure, instead, I found it relaxing. They said that playing in a competition is not relaxing, pressure came with the need to win competitions. In the junior team, this is not the case. It is a practice team, so to speak, to feed into the A team. I told them this is of no use to me, and I withdrew from the club.. I feel I am good enough for the A team. Why should I be in the B-team? I said no, I am no longer interested.

This excerpt was taken from our first interview together. The discussion that followed led to an exploration of the possible intentions of Nicolas's friends. During our third interview, Nicolas reported that he had gone back to the club, after doing some thinking. He came to believe that his friends had been genuine in their concern for him, motivating their behaviour. After explaining his illness and disappointment with not being able to play in the A-team to them again, Nicolas re-joined the club and was accepted back into the team.

This part of Nicolas's story illustrated the unfortunate consequences of a participant's reliance on the opinions of others, at the same time anticipating the views held by those around them to be negative. During the interviews Nicolas was trying to provide a rationale for his decision to withdraw from participation in an occupation that he valued above all others, including work. He realised during the interview (and subsequent reflection on the interview) that his friends might have been acting out of concern, rather than with intent to exclude him. The trend picked up during interviews was that participants often, passively, accepted real or anticipated negative views. Whilst they would ponder on the consequences and the unfairness of such views, they seldom confronted other people in order to confirm negative views, and then to challenge such views.

6.1.3. Balancing illness identity and worker identity

With the first occurrence of psychiatric impairment, participants would already have constructed an identity that was informed by their life experiences in the absence of psychiatric impairment. Such experiences might have included participation in work, or being a student, which led to the construction of a work identity. The occurrence of new experiences that are shaped by symptoms related to psychiatric impairment might be equated with the incorporation of an illness identity. For the purpose of this study 'illness

identity' should therefore be understood to mean 'the definitions that are created for and superimposed on the self as a person with psychiatric impairment'. One might for example consider the person who yields to symptoms associated with psychiatric impairment to such an extent as to choose a life with many restrictions, as having a strongly developed illness identity. This would be in contrast with a person who attempts to continue with life as it was known before the occurrence of psychiatric impairment, rejecting life style changes and not utilising support that might be available. Participants' life stories illustrated the need for a good balance in work identity and illness identity to provide the flexibility required for adjusting to the fluctuations that necessarily will occur. An over-reliance on one of these constructs tends to bring rigidity that disallows fluctuations in health that otherwise might have been contained without secondary disruption. It also gives impetus to strategies that are overly vigilant in restricting participation as a protective mechanism.

Participants who had their first experience of illness earlier in life, while at school or university, would have incorporated an illness identity at an earlier stage. Some participants seemingly incorporated an illness identity into their existing identity constructions with relative ease, others experienced great difficulty. When participants resisted elements of an illness identity, they seemed to be more determined to continue with their lives in ways that resembled their life before psychiatric impairment. The opposite was also true. However, the bigger determinant was not the ease or difficulty with which an illness identity was adopted, but the ease or difficulty with which a worker identity was constructed. Those participants who already had a well established work identity by the time they first became ill found the continuation of a worker identity much easier than participants who did not have such a foundation from which to proceed. The former group seemed to rely on being a worker in order to mediate the distress experienced as a result of psychiatric impairment.

In the absence of a worker identity, participants seemed less prepared to overcome the barriers that made entry into work difficult. Constructions of identity seemed to be absorbed in issues around preservation of health as a protective mechanism against possible relapse. Without a work identity to rely on for affirmation that they might succeed in work, participants faltered when they attempted to obtain and maintain work on their own. For example, Robert and Sharon were both top students at school and had been elected to leadership positions before they had gone to university. The first experience of psychiatric impairment during their student years seemed to derail them from previously held future plans to such an extent that they were unable to contemplate working for many years. In the following excerpt Sharon talks about being given an opportunity to enter work within the context of a supported employment programme. She mentioned that she did not succeed in finding work until she did this in a disabled capacity.

"I have noticed there is no stress barrier ...stress here at [the library], as I had in other libraries. Maybe because it is a semi-religious organisation, or the staff have been told that I am disabled, I was never able to work until I found a job in a disabled capacity. And fortunately I knew exactly what to do ... I've done proofreading, they put me on a 10-day computer course, which I managed to pass, ... every day there is something new to do, and I ... just all my talents have come back". [Sharon]

Sharon's life story illustrated an interplay between her illness identity and worker identity. Both had to be acknowledged and held in a particular balance for her participation in work to be enabled. The same was true for Donovan and Andrew who found that their ability to work was greatly enhanced by the support they received from Roseberry House.

Both had had repeated attempts to find work, with mixed success. The real problem was, however, maintenance of work. Donovan could hold a job for up to two months, but Andrew only lasted weeks. Both participants became members of Roseberry House and entered into the TEP. After a number of

temporary placements they both found jobs. This time they were able to maintain work, arguably because they were able to utilise the help that was offered to them.

6.1.4. Balancing constructions of 'helper' and 'helped'

Being in a position of needing help caused discomfort and feelings of ambivalence. It evoked seemingly contradictory feelings, on the one hand being appreciative and feeling cared for and, on the other, feelings of being weak, out of control or unable to look after self and others. Negative associations with needing help might have had something to do with the fact that people with psychiatric impairment usually need help from others only during phases of active illness, when they experienced relapse or during recuperation after relapse. Examples of the help that is needed during these phases vary, it includes curative and rehabilitative intervention, practical assistance, for example a place to stay, assistance with problem-solving and decision-making, and financial support to cover costs of treatment and also lost income. Participants' need for help obviously intensified when relapse was associated with impaired judgement. The main argument here is that being in need of help reminded participants of relapse; it therefore had connotations.

In contrast, participants valued instances where they themselves were in the position of being able to help others. The pattern was observed when participants spoke about hospitalisation, and about their lives outside the realm of work: being in a position to help others brought positive feelings and might have demonstrated to themselves their ability to make a worthy contribution. Whilst needing help was something participants disliked and that they accepted with some reluctance, being able to help others allowed them to feel needed, worthy and in control. In the quotation below Thalitha is talking about her hospitalisation. It is clear from the excerpt that she positioned herself as the helper, something she valued being:

".. you observe people also just in a slightly different way, and that makes one sympathetic towards other people, you know, I won't just make a split judgement on a person like, okay.. if they haven't done that, what is the reason, is there a reason, how are we going to find out, do we ask, who do we ask, do we ask the director, do we ask a parent, or you know, until you get.. until you get a better picture...

If one thinks of.. you know, psychology for teachers, you know, we certainly did not do in-depth psychology training at all. Which in psychology training you obviously get that, you know, because there's a problem, okay, don't judge the problem, is there a reason, what are the reasons, and you get a picture and you then make some sort of prognosis, it's not.. it's not in the judgement, you have to.. you know, is that.. it's .. will that be a workable thing, can we work with that person, with that result. As I say.. I had to learn that.. I actually had to land up in hospital to learn that". [Thalitha]

Seemingly an anomaly was that participants did not judge those that needed their help in the same way they judged themselves when they needed help. Some participants were, for example, outspoken about the need for reasonable accommodation to be implemented for people with psychiatric disability, at the same time resisting the idea that they themselves needed such accommodation.

Frustration arose when attempts to regain independence was hindered by those who continued to question participants' ability to be independent. Participants therefore seemed easily irritated when they felt they were being treated like children. Conflicting emotions about accepting help might have been the result of shame or helplessness experienced during those times when they did in fact need help. The unhappy reality for most participants was that there were times, even after relapse, that practical assistance and support from others was needed. Real gratitude and feelings of intense

irritation were often expressed in quick succession during interviews. This pointed to the presence of such conflicts.

6.1.5. Competing health views

Traditional views about illness and health are often in contrast with Western views of illness and health. Particularly in psychiatry a lot has been written about the differences in interpretation between Western and African points of view when explaining the cause and reason for psychiatric impairment. The detail and variation of these views, that were briefly introduced earlier, fall outside the scope of this study. The focus of this discussion will be on influences as they emerged from the life stories of participants.

Black-African participants alluded to conflicts that arose from having to balance competing views and beliefs. The first decision they had to make was whether to consult a traditional healer or enter into the government health system. The participants in this study all chose to seek help from within the government health system. For Nomisa this direction was influenced by a strong grounding in the Christian faith whilst Malixoli spoke about being comfortable with modern interpretations of anxiety disorder. For Siphon the issue was more clouded. His parents had renounced all traditional Xhosa practices and were expecting him to do the same. Siphon himself was torn between the interpretation his parents wanted him to follow and his own feelings that he should be closer aligned with the traditions of his community. Even though Nomisa and Malixole did not seem to have conflicting ideas themselves, they nonetheless were confronted by those that felt differently on a daily basis. Traditional views were in some instances vilified by Christian beliefs, while people who chose Western solutions were in turn marginalized by some members of their communities. Constructions of identity were therefore further complicated by ongoing decisions about alliance with one worldview or the other.

Sipho's internal conflict was emphasised during our interviews. He based decisions on one of two opposing worldviews that he had been living with for most of his life. The occurrence of schizophrenia brought to the fore different sets of choices available to him; these were underpinned by either a particular sectoral belief system (with a strong foundation in Christianity) that was held dear by his family, or the traditional isiXhosa belief system to which he subscribed. Sipho attributed much of the distress he experienced as a result of his illness to conflicts about how best to manage his illness. Sipho and the rest of his family held opposing views, causing a deep divide that separated him from especially his father.

Sipho explained how his family convinced him not to use the medication given to him on discharge from hospital. Instead, they thought he would be healed through prayer. When Sipho's dissatisfaction with his life, and his frustration with the symptoms he was experiencing remained, he chose a solution in keeping with isiXhosa traditions, that of undergoing initiation. This was something that his family did not agree with. Sipho was therefore caught between gaining the acceptance of his community that consisted predominantly of isiXhosa-speaking people who held traditional views. For them initiation is considered an essential step to be taken by boys to become men. Without undergoing an initiation ceremony in a proper initiation-school, a isiXhosa male would not be taken up into the community as an adult. He would for example not be allowed to marry women from certain families and could not rely on assistance from the larger community in times of crisis. In the excerpt below Sipho explains his unhappiness that arose in part because of needing help and in part because of the conflicting belief systems.

"Sometimes at home I don't feel I belong there. Everything I want I try and do it on my own. For example when I went for circumcision school my sister who is married helped me. At home they did nothing for me because they believe that I am a man so I must do all my things by myself. I don't go to

school. I am not working and those are the other things that worry me. My family goes to church that does not believe in African culture. But I went for circumcision because I was thinking about the future of my children. So now its like I don't belong there. Everything I want I try it by myself, even the clothes that I am wearing I suffered getting them". [Sipho]

Nomisa spoke about the same conflict between traditional and Western beliefs in the management of psychiatric disability. She told me that many African people would see the illness as having been brought about by the Tokolosh²¹. This is believed to happen when somebody is bewitched by another person, usually somebody who had been angered by the person experiencing the problems. Choosing one of these dominant worldviews above the other brought conflicts to the fore that otherwise might not have surfaced, and resulted in difficult decisions. Nomisa told many stories that revealed a tendency of people confronted with psychiatric disability to shift between worldviews in their attempt to find explanations and solutions. These shifts cannot be made easily as the two worldviews in question are diverse. Shifts would therefore result in disagreements such as experienced by Sipho. Nomisa shares her views of these conflicts in the excerpt below.

"I think they.. few, why I'm saying that, there's a lot of people outside there who's sick, walking around, dirty.. eating in the dirty bins, because they can't think. If you can think, if they.. if they can be like myself, I think.. .. they will be okay, I think really, because I didn't think before, I was sick. I was walking up and down, but my sister was there for me. Even if they can get someone, I think that can be better...

Where there are families.. it's the families.. they, they don't care for them. Um.. ..other people, they think if someone is sick like.. if you remember last

²¹ A very small male creature that is strongly associated with having evil intentions. Mechanisms designed for protection against the Tokolosh are used daily. One such mechanism is to place all beds in the household on bricks because it is believed that the Tokolosh would not be able to reach. The Tokolosh could also bring good fortune if appeased.

time I was telling you that if.. ..their families, or other people, they can take them to.. here to hospitals, taking the medication, they will be okay. They just taking them as the mad, some ones they won't be healed, won't be okay, you see what I mean. They just don't care for them whether they okay or not, they just don't care for them. They just telling themselves "Oh! she's mad". Because what they.. the.. the.. word I don't like they using.. it's 'mad'".
[Nomisa]

Nomisa lamented those who held on to traditional views, thereby not using Western medication that she believed was required. She thought they needed education and identified this as the main reason for her active involvement in the running of a support group for people with psychiatric disability in the community. Nomisa, a deeply committed Christian, explained how those who were seeking help from traditional healers were caught in a destructive cycle. In her sharing of her concerns for these people Nomisa explained that people with psychiatric impairments are feared by others in their communities. Nomisa herself did not experience negative attitudes from her community. She explained this was because of the active contribution she was making in her community. She would organise prayer sessions before funerals and would be of general assistance to all those who needed her help. This, in Nomisa's opinion, negated the fear people in the community might otherwise have.

6.2. Strategies for healthy living

Experiences associated with having a psychiatric impairment, together with subsequent service interventions, made participants aware of the need to approach aspects of their lives differently. During interviews, participants often highlighted their intention to change particular behaviour patterns that they identified as less than ideal. For some participants, the need for change was motivated by a need to prevent the horror of having to live through another relapse. Others identified aspects of behaviour that they had always

considered problematic and that they now wanted to change. For a small number of participants the onset of psychiatric impairment meant that they no longer had to live up to internalised expectations they perceived others to have of them. Freedom from previously felt external expectations allowed for re-appraisal of goals, bringing these closer to the personal choice of the individual.

The categories that emerged to make up this theme were closely related and it was therefore difficult to tease out how they related to one another; these were *self-imposed restrictions*, *anticipating relapse* and *maintaining equilibrium and holding uncertainty*. It was not always clear whether the strategies used by participants were motivated by the need for healthy living, with the positive spin-offs being an experience of wellness and being in control, or whether it was motivated by the need to prevent relapse. Participants placed different emphasis on the two categories, but both were used by all participants. When participants feared relapse, their main strategy was to hold back from opportunities in order to prevent stress that they associated with unfamiliar expectations. This was done as a mechanism to reduce stress and to prevent fatigue, and ultimately prevent relapse that was strongly associated with too much pressure or burnout.

6.2.1. Self imposed restrictions

The main mechanism used to prevent relapse was to hold back, thereby placing restrictions on the occupations participants chose to do. When activities or situations were judged to be potentially stressful, participants would usually try to avoid them. Some participants increasingly linked particular activities or situations directly or indirectly to relapse. For some participants, restrictions of behaviour became a preoccupation that emerged as the foundation for most of their decisions. The preoccupation with preventing relapse often led to non-participation in work-occupations. The

intensity of participant's focus on preventing relapse might be understood when it is recognised that several factors reinforced it.

The unpredictable nature of psychiatric impairment led to participants' need to invest their energy into finding explanations for relapses experienced and how to prevent them from happening again. The 'out of control' experience of having psychiatric impairment seemed to contribute to participants' need to develop a personal framework with 'cause' and 'effect' built into it. Every participant in this study shared their ideas about the causes of either their first 'breakdown', or subsequent relapses during the interviews. This was usually done together with the strategies participants had identified for themselves to combat recurrence of relapse.

Participants generally emerged from a relapse to face the same stresses they identified to be the 'causes' of their illness, however, they did so from a more vulnerable position. They were now living with the evidence that they had not been 'strong' enough to 'cope' in the first place, hence their 'breakdown'. A reduced belief in own ability to maintain health meant that participants restricted their participation by steering clear of what they perceived as potentially stressful situations. Christo was reflecting on the jobs he had been doing since discharge from hospital one year before. He never contemplated not returning to work, but did not consider himself able to cope with the same pressure he experienced whilst working as a site surveyor. This was something he did successfully for twelve years.

"Ja, kind of you know.. just.. suddenly there was this, you know.. we were when we started the job.. there was no.. time-limit emphasised.. there was no.. .. limit on your funding, your funds, you know.. so we.. we basically went into the job.. quite casually.. and then suddenly near the end it was a case of.. move it, move it, move it.. you know.. you're using too much money.. this, that and the rest.. and, and, and.. that- when that happened.. .. I just felt.. I knew that, I still wasn't ready to cope with that kind of stuff. I felt.. I'm not ready to cope with it because it will just rip me apart.. inside. And .. it

scares me.. honestly.. it scares me to.. to try and imagine having to go back into.. the real world, as I said to my friends in my cell-group. It was like.. when I was working with my friend, and then I went to work for my brother in law and then I went to work for.. this maintenance company.. I was.. because it was.. the way that it was.. I had a lot of support.. .. people were very encouraging, there was no.. hectic tempo.. like I'd experienced in my past job". [Christo]

6.2.2. Anticipating relapse

The pattern of life with a psychiatric impairment was one that brought much uncertainty and reduced participants' ability to develop a sense of personal causation²². The generic characteristic across different psychiatric impairments is in the pattern of unexpected relapse, followed by undetermined periods of recuperation. The pattern included those times during which participants were not aware, or in control of aspects of their own behaviour, usually during the worst phase of active illness. This aspect of psychiatric impairment brought major disruption to identity.

The irony was that whilst participants' behaviour during relapse was often not in line with reality, the damage that resulted from such behaviour was real. Some participants spoke about rebuilding their lives, while others would use words such as "picking up the pieces". It became evident that all participants lived their lives with a sense that healthfulness is fragile.

Participants were particularly concerned with finding explanations for the pattern of their impairment; this was closely tied with the need to identify factors that caused fluctuations in their health and wellness. Attempts were made to isolate factors that caused the illness in the first place and those that

²² A collection of dispositions and self-knowledge concerning an individual's capacities for and efficacy in occupations Kielhofner, G. and Forsyth, K. (1997) The Model of Human Occupation: An Overview of Current Concepts, *British Journal of Occupational Therapy*, **60**, 103-10..

brought subsequent relapse. The inevitable uncertainties with which they were left seemed to reduce participants' belief in their own ability, and therefore the development of personal causation. Participants voiced their fear of relapse repeatedly, often whilst explaining preventative strategies. Such strategies were dominated by a need to minimise stress, often by avoiding particular occupations or situations. In other words, participants seemed to live in apprehension, doing what they perceived to be within their power, in order to prevent the recurrence of symptoms or full-blown relapse. This meant that the impact of symptoms on identity was not restricted to periods of relapse, but that the impact was ongoing. Sharon, who returned to work within the context of a supported employment programme after seventeen years of unemployment, is talking here about the strategies she used to avoid relapse. The distress brought about by symptomatology is clearly evident:

"So I work 4 mornings a week, and 4 mornings a week I can manage easily, work starts at 9 and ends at 12. So I have time to get up in the mornings, have breakfast, have medication, take the bus to work, and on Thursday afternoon when I finish for the week, I am tired.

I only hear voices occasionally when I'm really stressed out and tired, and that's in the afternoon when I've worked all day, and then I take a pill and go to sleep, wake up refreshed.

You know, 'cause schizophrenia is a horrible affliction, and it.. you hear these changed voices, and if you listen to your voices you will land up doing unspeakably ridiculous things, so the whole point is.. to differentiate between ones inner- and outer realities. You know, to see that the external reality is not.. the same as one's internal reality. It's this differentiation, which my psychiatrist taught me years ago, it's always in the front of my mind, you know,. and I wouldn't wish it on my worst enemy. It's horrible. I don't think I'll ever get back to as I was in matric, I was a prefect, but.. ..with the help of God.. I may become .. um.. member of a group of the [Name of place of work] you know, an active member of staff". [Sharon]

Fear of relapse, and the restrictions imposed on self to try and prevent relapse was one of the main influences on the lives of participants. The time and effort that went into preventing relapse came as a surprise. Participants vigilantly scrutinised the demands of the day in an attempt to avoid stress that was consistently cited as the cause of relapse.

6.2.3. Maintaining equilibrium and holding uncertainty

Fears associated with their psychiatric impairment seemed to result in heightened attentiveness to influences that could impact on wellness. Participants seemed to live on the alert, scrutinising how well they were doing at any particular time. They were sensitised to appraise the state of their own well being on a day-to-day basis and invested time to consider the impact of many factors on their wellness. At the start of each interview, and often during interviews, participants would summarise 'how they were doing'. This would usually involve a description of mood, and the stress they were experiencing in terms of the extent to which life events fell within the limits of their perceived competence. Mostly, participants seemed concerned about the extent to which life events were within the realm of their own control, and could be engaged with safely.

Another issue that reinforced participants' pre-occupation with prevention of relapse was the unpredictable pattern of psychiatric impairment. Participants had to accommodate extraordinary shifts, sometimes brought about by a change in aspects of identity that determine the most personal dimension of a person, such as mood, ability, motivation or confidence. When considered with an understanding that psychiatric disability is chronic in nature, maintaining equilibrium becomes a life task. Donovan, who negotiated a permanent administrative position for himself after he had completed a TEP in

the company, talked about maintaining equilibrium. Donovan had been working successfully for this company. He explained:

"And then also.. .. basically, what.. what's helped me a lot.. initially it was.. it was very difficult.. finding work and being able to keep the job. I actually found it very, very difficult, initially.. mainly I think because you don't understand exactly.. .. what's happening to you. People may explain to you, but.. .. you don't really grasp the impact it has on your life. And you kinda want to go on.. .. how can I say.. .. doing things exactly the way you had before.. .. having become ill. And you kind of find that you.. you.. you're a bit disjointed.. .. and the balance is not there anymore, and you somehow have to find an equilibrium for yourself. And it's very important that a person.. realize that you have to be comfortable with who you are now, you no longer are what you used to be, it doesn't mean that I don't feel that I'm less a man that I was before becoming ill, which was 1989.. only.. it's much more difficult because I think the challenges that faces you.. .. has also got a lot to do with your own attitude, your own.. .. self-image.. .. and that you.. you, how can I say, you.. almost like.. let's say it's falling from your little pedestal and it's difficult for a person to get up and start all over again. Because that's basically been my experience". [Donovan]

It seemed the more participants were able to tolerate change brought by the pattern of psychiatric impairment, the better they were able to incorporate the changes that were necessitated by psychiatric disability. This was because such an ability made them flexible and more able to accommodate uncertainty. The opposite was true, and participants who were uncomfortable with change were more easily unsettled and became more rigid in their attempt to control their environment by restricting their participation in a range of occupations.

6.3. Approaching life differently

Life with a psychiatric disability required approaches and strategies that participants would not have needed before. However, some participants spoke about a permanent re-orientation that was almost existential in nature. The categories that will be discussed to support this theme are developing constructions of difference and living within the Will of God. The third category was more difficult to name, so 'surviving the worst' was used to capture participants' ways of thinking that suggested, and celebrated, their survival of what was usually a horrible experience. In their survival of the worst that could happen to them, they found freedom to change aspects of their lives that they might not have considered changing before.

6.3.1. Developing constructions of difference

Most participants would at some stage during our interviews use terms to describe the world into which they did not fit. They described this world as "the real world", "the normal world" or the "world out there". Other participants did not make such distinctions, but would describe people without psychiatric disability in terms that set them apart; referring to such people as "them" and "they". Participants consistently perceived themselves as different and separate. They not only set themselves apart from people without psychiatric disability but also used narrative that showed them up as being less able, less worthy or weaker than 'normal' people. Although some participants spoke about experiences of stigmatisation and would criticise faulty beliefs held by society at large, many did not seem to question the accuracy, or the fairness, of such beliefs or attitudes. Siphó's quote below depicted the acceptance of difference that most participants shared.

"If those people would understand my personality and the condition that I'm in and the way they treat me.. they should take me as if I am like them,

although they know that I am not. So I think that would make me comfortable working with other people". [Sipho]

When constructions of difference were very strong, this interfered with participants' construction of a worker identity. The reason for this relates to the fact that work environments are dominated by non-disabled people and the stigmatisation of psychiatric impairment.

Suzaan's construction of her own difference was all-pervasive. She could not capture in words how she was different, but her narrative set herself apart from her co-workers, her friends and her children. When asked about the experience of 'difference' directly, her answers would be vague and she would not really commit herself to answering the question. However, two types of 'difference' were captured by Suzaan. When her family was very supportive and visited her in [Name of psychiatric hospital], she felt different in a positive sense.

"My family was always there.. and my mother and my brother are overseas but my sister and my daughters, my two daughters.. they never let me down through all those times- they were always visiting. A lot of people just.. they just don't they just call or they will.. that, that made me feel different. You understand?" [Suzaan]

Yet, at work, when she was the focus of conversation amongst colleagues she felt different in a negative sense.

"I think so. I think so.. If I, If I just started there or worked there a year or so.. I doubt whether.., they would have kicked me or I would have left. I personally don't think I would have.. because a lot of those people work there long as well. So , whether, whether they ask me the question out of curiosity or concern.. it didn't bother me, I just answered it and I said that is enough don't ask me any more". [Suzaan]

Sipho had the same all pervasive way of describing himself in ways that set him apart from the rest of the community. He seemed to ascribe most of the difficulties he experienced to the fact that he was considered being different from his own family and from his own community. Like Suzaan, he was not able to explain in which ways he considered himself to be different. However, Sipho's construction of himself as different and apart from others became the reason he chose to actively withdraw from social, community and family life. He lived in a small room in the backyard of the house in which his family lived and explained that he would have to decline work offers that involved working with people without psychiatric disability. Sipho emphasised that he was alone and also very lonely.

"My life is up and down because of my sickness. I've been sick and then feel better, and sick and then better, so my life is like that. My life is unpredictable. I don't feel like I am like other people. I feel I am different from others". [Sipho]

When, during the interview, the issue was explored in order to gain a better understanding of the reasons why Sipho saw himself as being different, he found this upsetting. Showing his irritation, Sipho insisted on his difference, based only on the fact that he had a psychiatric impairment. Sipho seemed to base his construction of 'the place' of people with psychiatric impairments in the community on the views of the larger community. His internalisation of society's views seemed to have stripped away his own power to challenge something that brought him much pain. He not only accepted the status quo, but also asserted his own difference.

"Yes, that's one of the things and when we talk about my health and others because there are people who are like me who have nothing. But on my health side I know the other person does not have what I have so I am different from him. Secondly the other person has never experienced a mental illness so that makes me different. I am not different on external appearance from other people but deep inside me I am... .. I am different in

my own eyes and also in the eyes of the people whom I have told my story, like you and [Name of CHW], but other people don't know that". [Sipho]

Based on their own ignorance prior to first experiencing psychiatric impairment, and on their subsequent frustration to explain their illness, participants anticipated ignorance and negative attitudes from those around them. They operated on the assumption that people without psychiatric impairments did not understand, were not able to understand in much the same way they themselves were not able to fully understand. This seemed to contribute to a feeling of being different and apart from those around them.

6.3.2. Living within the Will of God

Participants were affiliated to different faith communities. With the exception of four participants, they looked towards God for understanding (making sense of what had happened to them), meaning (finding a reason why) and for guidance about strategies that could be used.

Understanding God's Will for their lives and identifying a possible purpose for their disability brought much comfort to participants. While for some, their faith was relied on to make sense of what had happened to them, others changed their lives in order to bring a closer alliance between the lives they were living and the life they understood God wanted them to live.

Christo spoke with much conviction about his decision not to re-enter what he termed "the real world". He saw an opportunity to combine work with doing something for God and for other people. He spoke about work for God as a 'blessing' that he could actually experience physically, spiritually and emotionally. He also saw it as a defence against his depression. Therefore, it is something that provided meaning and purpose, at the same time making him feel better about himself and reducing the negative impact of psychiatric

disability. Interpreting God's will for his life, and living his life accordingly, became the single most important mechanism used by Christo to re-build his shattered life.

For some participants, like Robert, living the life he understood God wanted him to live also meant that it was less demanding and possibly less harsh. Robert's faith assisted him to accept a level of participation in work that might be considered 'low key' for somebody who has a bachelor's degree and future plans to be a lawyer. He did not contemplate challenges that fell outside the activities and contexts in which he felt familiar. Making sense of his choices within the realm of his faith, might have made it possible to accept a life without participation in mainstream work. Never having worked was justified by him re-defining his contribution within the Will of God. In so doing, Robert's identity needs might have become less reliant on him being a successful worker.

Interpreting their experience within God's Will seemed to bring comfort, and aligning participation in work to serve God brought a life with more meaning. For some it might have offered 'a way out'. God's bigger plan, and the fellowship experienced with people sharing their own faith, was something that participants relied on to make sense of the hardships they experienced.

6.3.3. Having 'survived the worst'

A number of participants explained that they had always found it difficult to live their lives in accordance with their own wishes. It seemed that they would behave in particular ways because they did not want to disappoint significant others who held particular expectations. When they then experienced psychiatric impairment they gained the impetus to make changes in accordance with their own wishes.

Chriselda and Dorothy are good examples; they both felt free to implement change in order to meet their own needs better. Dorothy had earlier agreed to move back into her family home, where she did not feel safe, after the death of her stepfather. Being the only breadwinner in her family, she felt compelled to return home to help support them. This was done at great personal cost. Dorothy had been living within a religious community with her daughter in circumstances that she referred to as "the happiest time of her life". Dorothy spoke a number of times about her need to pray; her wish was that she would end up in a place where all she had to do was pray. She laughed at this, saying that she never knew this wish would come true. Dorothy was referring to her time in hospital, when she could prayerfully re-think her decisions. She spoke about her experience of being ill and said "I needed it". Being ill signalled her distress that she was not able to express at the time, and made people understand that her needs had to be considered. Dorothy's illness brought relief as she felt, for the first time, permitted to express her own needs and entitled to plan around these needs.

During our last interview, Dorothy shared that she had started to make very tentative plans to move out of the family home. She devised a compromise in which she would pay towards her family's expenses, but live on her own. It also meant she would no longer give her entire salary to her mother, as she had been doing. Having a psychiatric disability somehow allowed Dorothy to give some priority to her own needs, and justified making decisions about changing her life.

Chriselda spoke about having a low self-esteem, which she ascribed to her tendency to put too much value on the opinions of other people. She tried for most of her life to live up to the expectations she perceived other people had of her, yet did not feel that she was able to meet these expectations. One obvious example was a relationship she had allowed to continue for seven years, despite knowing that it was not a good one. She explained how all this changed after she had had her first experience of bipolar mood disorder.

Using the expression that “the worst had happened”, she explained that she no longer needed to uphold the image she thought others expected of her. This allowed her to align her behaviour and decisions more closely with a renewed sense of self she was experiencing. She spoke about having had to confront herself when she was at her lowest, stripped of all pretences. This experience seemed to free her in some ways. She spoke about being able to see herself for the first time:

"It's like um, very concerned about others opinions and always asking them um what do you think about this, do do you think I should join this club, do you think I should go here that kind of thing, and um.. now it's like, you know I try to - you can't please everybody. So you can do what.. you can only do what you can do.

After this happened to me, it was um.. um.. the person I was before it happened to me was um.. it was um.. you can say it was a complete stranger to me, and um after that it was um sort of picking up the pieces, um.. um.. getting to know and remembering um.. who I am. Who um, what's it, um getting to know my personality and my sense of self. Getting that back again, whereas before it was um just sort of mindlessly plodding through life".
[Chriselda]

Chriselda had always been sensitive to the image she portrayed. She often spoke about being a fashion designer, the image that had to be developed and upheld in order to be considered a good designer. She used words like “fake” to describe the world she worked in. The need to behave in ways she perceived others wanted her to behave seemed important in her line of work. However, Chriselda seemed to apply this attitude to the rest of her life. Once “the worst had happened,” she felt that whatever image others had had of her had been shattered. Her intention was now to speak about her feelings more honestly and to behave in ways that would meet her own needs better. This included confronting people when this was required, at work and at

home. Chriselda experienced a new found freedom, and a responsibility to organise her life in ways that would ensure her own wellness.

6.4. Identity rebuilding strategies

Participants focused much of their energy, and a range of strategies to rebuild their lives. Some of the strategies fell within the realm of searching for meaning and attempting to make sense of what had happened to them. Participants also attempted to answer the 'why me' question. Strategies they used to put their lives back together again included finding a positive outcome from having a psychiatric disability.

6.4.1. Finding positive outcomes

Finding positive outcomes resulting from their psychiatric disability was a trend through most interviews; exceptions were George, Malixoli and Joanna. Emphasis was placed on finding positive spin-offs from having psychiatric disability while participants continued their existing way of life. In extreme cases, for example Thalitha, positive spin-offs were seen to make experiencing psychiatric disability worthwhile. For other participants finding positive outcomes made having a psychiatric disability more bearable. It assisted participants to accept their disability better as shown in the excerpts below.

"...I'm going to say a very funny thing: (Short pause) 'I thank God that I actually have this illness.. because it has given me an insight that I wouldn't have had otherwise'. It's making me less judgmental, especially since this last experience and the way I was treated, and the way my treatment took place". [Thalitha]

"Yes I am still working at this place, and.. in my case I find that.. it's .. things are looking much, much better, it's almost like things took a complete 180 degree turn. It's because I decided to take part in my life instead of just watching my life go along. And .. some days I have my 'ups'.. some days are up days and some days I have my 'bad' days. [Name of psychiatric hospital].. .. in retrospect, it was, it was.. it was a good place for me to discover myself again.." [Chriselda]

Positive outcomes included relationships. Participants spoke about a new appreciation for people they might have overlooked in the past. Relationships with friends and family took on new meaning.

"...my dad and I chat the other night and he said 'for thirty one years.. you never saw the things people did for you Christo, you were so busy with.. your own things'.. but now after that- after what has happened.. uhh, I see the.. effort that my parents make.. to.. to show their love.. ..and the same with my friends.. I definitely have a different outlook with regards to my friendships. So.. ..that, that, that's definitely been.. a, a.. a plus.. that's something- that's why I don't want to get back into.. the rat race.. of work.. because you kind of.. you lose that.. everything just gets blurred..." [Christo]

Interestingly, even when relationships deteriorated or were terminated, participants often interpreted this to be a good outcome. This was because these relationships were considered to have been insincere or destructive, therefore it was better to terminate rather than continue them when they were 'false'.

6.4.2. Reluctant reliance on others

Assistance and support received from employers, co-workers, family, friends and service organisations, such as Roseberry House's TEP was repeatedly mentioned by participants. While this did not come as a surprise, the extent to which it enabled continued involvement in work was indeed a revelation.

Feelings of ambivalence associated with needing help were discussed in 6.1.4. Despite the ambivalence experienced, reliance on others emerged as a strong influence that positively impacted on maintained participation in work. Support at work will be discussed in Chapter 7.

Support from family brought encouragement and seemed to soften the distress associated with having a psychiatric impairment. For some participants, having family support was motivational in that they wanted to do their best for their families. Participants who were able to rely on support from family seemed less alone in their struggle to regain equilibrium and focused more on being well again. Some of this is illustrated by Galiel talking about the support he received. This is made more significant when read with the knowledge that Galiel had been suspicious of his wife at the time, something that was a symptom of paranoid schizophrenia.

"..the support I had all around, you know my family was won.. especially the family that I live with, my in-laws and um .. my wife, they were just wonderful, you know, they just understood. You get a lot of people ..um I mean I have family members, until today who haven't asked me what really happened, or what kind of illness do you have. You know they just kind of like ever since that time they avoid me.. it's you know, it's because, probably because.. I don't know because they don't understand the situation.. ..but um ..I mean my, my family here were very supportive, they understood and um ..my wife used to sit up with me at night, I wouldn't want to go to sleep, I would sit in that chair here, and just.. you know, I would be scared to get into bed.. ..and things ..going on in my mind, and she would sit on the couch there and just ..be awake, just, we wouldn't speak, but she was just there. I knew that she was there for me". [Galiel]

Some participants, for example Nomisa, did not show any reluctance to accept help from others. She relied on others in times of difficulty and considered the fact that she was able to do this a blessing. In the absence of her family, she relied on friends and members of her community for support.

Other participants, for example Chriselda, were surprised by their own capacity to accept help at times of crisis, but soon insisted on returning to their status of self-reliance.

"Getting back to society was a bit strange.. and.. what overwhelmed me [crying as she speaks] was the.. the .. the compassion of people. It was.. it was a big surprise.. and .. the.. how willing people are to help you out. That was.. it was a big surprise to me because I used to be.. .. 'I can do this on my own, I don't need anybody's help yadee, yadee yadee'. And.. uhh.. my sister's circle of friends, and my circle of friends.. just sort of phoning up, checking how I am, inviting me to spend an afternoon with them, kind of thing. Then sleeping over for a week at a friends place, her husband was on business trips and she was alone with the kids, you know, sort of having a holiday.. and just relaxing". [Chriselda]

Robert relied heavily on family support and in his case reliance on others did not lead to maintained involvement in work. In fact, the level of financial and practical support he was receiving from his family might have contributed actively to his decision not to participate in work.

"My parents told me time and time again that they will provide for me, and they will, - and I've got my disability grant. If I stay single, a bachelor, then I'm sure I will be able to survive until I finally die. If I had a partner, I don't quite know how that will all work out. I would love to have a job, but it's a dream, at the moment any way, the technicalities getting up for work, when you just don't feel like a full day at work. I'm still a little bit weary, a bit scared of plunging in where it might be too deep for me at the moment. So what I'm doing at the moment, is taking it day by day, and making the effort each day. Like with my sport, trying to get fitter, more active and day by day working towards this goal and then eventually getting a job one day. They do have a TEP program here that might be the next step. Although the work gets, "entry-level" work and it is half day, and that might be the next step. That might be the next option". [Robert]

It became clear through the interviews that participants found solace in the relationships that offered support during difficult times. They also took encouragement from people who were significant in their lives. Some participants were more reluctant to rely on others, and as a result were more ambivalent about being in a position where they were not independent. Such participants seemed to be motivated to return to work in order to regain self-reliance. Other participants were motivated by the “do good” for those who had shown their support and stood alongside them in difficult times. The result was return to work in order to take up caring roles previously fulfilled. Comfortable reliance on others seemed to possibly reduce the impetus to participate in work.

6.5. Managing stigma, ignorance and prejudice

6.5.1. Alienating consequences of impairment

Changes associated with impairment usually affected the very core of a person’s being, their feelings, their thoughts and behaviour. This ‘power’ of psychiatric impairment to affect those aspects that a person uses to define and understand identity was, in my opinion, the main destabilising factor. Experiences of alienation that participants had experienced include:

- ◆ A father who did not trust himself to be alone with his young children because he experienced paranoid ideation and worried that he might harm them.
- ◆ Voices instructing people to do things that go against their religious beliefs and against their set of values that always guided their behaviour.
- ◆ Finding a previously satisfying career unsatisfying.
- ◆ Finding that good relationships changed, in part because of actual behaviour (that often occurred during relapse), in part because family

or friends lost their respect for the participant or looked at them differently.

The alienation that participants experienced seemed related to a mismatch between the identity they have come to know and the identity that was affected by the psychiatric impairment. It follows that the more these changes went against the participants' sense of themselves, the more alienating the experience. Alienation however also came from a mismatch between the demands of the environment and the participants' construction of their own ability. This was especially true if participants were facing opportunities to get involved in occupation that were different from their interpretation of the 'level' at which they performed before having a psychiatric impairment. For example, participants who were busy with tertiary education, and with no work history, found it extremely difficult to identify and make use of opportunities. The issue here was not only confidence, it had something to do with not being able to consider themselves as belonging in the contexts that now offered opportunities.

The feelings experienced when participants were expected to perform in contexts that did not match their perceived level of competence were not easily explained; whilst participants were often over-qualified and had the required skills. A strong trend was seen in which participants prevented themselves from engaging in opportunities in which they could not be sure that they would comfortably meet the demands posed. Participants would speak about opportunities with much excitement, only to change their minds about becoming involved. Most participants were not able to consciously reflect on this trend; instead it was a pattern that was picked up in their behaviour. A few participants had been conscious of this tendency and spoke about holding themselves back. The alienation that is associated with being in situations for which participants felt ill-prepared is clearly demonstrated in the excerpt from an interview with Robert.

"Yes I think so. I'm familiar with Roseberry House now.. , and if I'm to break new ground and go into unfamiliar territory, then it's got to be slow, it's got to be slow. .. that's.. I'm scared, I'm scared of going into unfamiliar territory.. because .. I don't want to.. fail.. I don't want to.. ..have my confidence knocked once again, you know, as far as work goes and.. .. familiar.. I'd say Roseberry House is familiar, ja.. .. (pause) but with also lacking, lacking in work experience.. is something.. thatif I had to apply for a, for a job.. then that would be.. moving away from Roseberry House and going into meeting new people- that's a big thing.. the buildings around me doesn't bother me that much, it's the people.." [Robert]

The severity of alienation experienced therefore related to the process of incorporating a changed identity into existing life-spaces in ways that enabled participants to feel that they belonged. Galiel, for example, spoke about his one experience of schizophrenia in ways that suggested it was something that 'came and went'. He had been greatly affected by schizophrenia when he was actively experiencing symptoms and was now convincing himself that he would no longer be affected by it. By attempting to keep his impairment completely separate from the rest of his life, Galiel was seemingly trying to put the alienation that made him so vulnerable behind him. He actively resisted the impact of psychiatric impairment on his life, re-building his life to resemble the one before his illness as closely as possible. It was not yet clear whether this strategy would make people more vulnerable; as I suspected it might. Galiel's behaviour during interviews confirmed for me that he needed to keep the experiences related to psychiatric impairment neatly separate from the rest of his life. Interviews with Galiel were shorter than with other participants. He answered questions politely and was positive about his participation in the study, however, his answers were factual and brief. This strategy seemed to leave him more vulnerable than participants who made more allowances for the impact of their illness to be an acknowledged part of their lives. I do not mean to imply that episodes of relapse were less threatening or less devastating to other participants, only that they seemed to incorporate change and imperfection into their identity. Such integration

seemed to increase the comfort with which participants were able to talk about their illness. More importantly, it seemed to reduce their sense of alienation. This was demonstrated by Thalitha's attitude toward her impairment that was discussed earlier.

6.5.2. Environments characterised by stigma and prejudice

Stigmatisation of psychiatric impairment and the stereotypes that are confronted in attempts to participate in work have been presented in the first four chapters; these will not be repeated here. It should however be emphasised that all participants lived in awareness of society's stigma of psychiatric disability. Some participants would single out the issue of stigma and speak about their impressions of it. Donovan, who found work for himself now had a permanent position. He was doing well, but still clearly aware of stigma.

"Ja...I've been working for some time. I think for me the biggest problem I actually had was.. um.. or even still is...um...people's attitudes. Um.. and also basically ignorance when it comes to mental illness...lots of people think, or have this idea that.. um.. a person with mental illness is...um...let's say,...um you're crazy, or your mad...um ..and they somehow link that with people who has either got chronic...um...um ..mental disorder, or...um...even the criminally insane, and they look more at the...um...that negative side of things; and ...um.. it seems to me ...um...like a blanket attitude that they have towards you ...um...the stigma is still out there and I think some of the employers, actually for me, as far as my experience is, ...um.. lots of them is still ignorant when it comes to mental illness ; and...um.. basically,.. basically they see you more as a danger than an advantage to them um.. in the work place um.. Whereas...um...maybe there's...as far as I'm concerned, there's actually adjustments they have to make...um...when you've someone with a mental illness which...um.. which has been diagnosed properly and where...um.. your illness has been managed...um.. well by both you, and

*...um ...either by a therapist or a doctor...um or whatever, you know".
[Donovan]*

Other participants did not separate the issue out in this way, but their narratives would reveal their separateness and their need to prove themselves worthy of being considered a person, not unlike others.

6.5.3. Balancing issues of stigma, ignorance and disclosure

Attitudes towards psychiatric disability - participants' own and that of other people, shaped decisions about work. Participants themselves might have harboured feelings of prejudice towards people with psychiatric impairment before experiencing it themselves for the first time. Some participants continued to talk about others with different psychiatric impairments in ways that demonstrated such stigmatisation. Furthermore, participants seemed to trust the opinions of others better than their own when it came to their being acceptable. This kind of reaction may have been created by those times when participants' trust in their own ability to judge for themselves had been shaken or when their judgement might have been clouded. The result was that participants did not scrutinise the fairness of others' attitudes towards themselves sufficiently.

Some of the difference that set participants apart seemed to originate from the views participants themselves held before their first episode of psychiatric impairment. Some people grew up with members of their family who lived with psychiatric impairments, this informed their views. Nicolas and Galiel both had negative experiences of mothers who were hospitalised. Others, like Thalitha, Chriselda and Jessica recognised the symptoms they experienced to have been noticeable in the behaviour of their parents, but did not have negative associations. However, most participants shared similar views to that of mainstream society. Attitudes towards people with psychiatric impairments

were mostly negative, albeit relatively unformulated and clouded in mystery and misconceptions.

Disclosure seems to be the one way of managing experiences of stigma. The issue of disclosure is a complex one, with the processes of reasoning to judge each instance of disclosure on its own merits being something that participants seemed to consider carefully. Jessica, who initially did not disclose her disability to anybody, spoke about issues of competence all the time. The paradox here was that she received messages from employers and co-workers indicating their view of her as a competent beauty therapist. Jessica did not believe this to be true; instead she explained with some agitation that people did not know her. Jessica's disregard for feedback from others seemed to have something to do with her own internal struggles about her competence. She spoke about being a fraud, and explained that she "looked the part". In the quote below, Jessica was sharing one instance in which she disclosed the fact that she was living with a Bipolar mood disorder to a co-worker. This disclosure on Jessica's part was an exception to the rule.

"...she said "you took all the wind out of my sails - I'm gonna tell you something Jessica, the problem is, you look the part". (Pause). You look the part. So.. it's a facade you know, , that's why I tell you I can push through that I'm capable.. because.. if you tell me to dress that way, I'll dress that way, if you tell me to not smoke and not chew gum and to be polite I'll be those things..." [Jessica]

Some of the turmoil Jessica experienced at work seemed to have something to do with the fact that she did not disclose her disability. She would feel alone and isolated in her struggle to work with what she termed invisible diseases²³. At the same time as needing to feel understood and accepted, she

²³ Jessica was diagnosed with having an attention deficit disorder and dyslexia as a child. These impairments made learning difficult. She would dress carefully to hide prominent scar tissue that resulted from a burn she obtained as a child. She explained that all of these were invisible to people out there in society.

needed to hide the difficulties she was experiencing from people at work. Much later during the research process, significant events contributed to her disclosure. Jessica was now working as a beauty therapist in an environment in which she had fully disclosed her disability to her employer and co-workers, as well as many of her clients. With her disclosure, she also broke the 'three-months at one place' work pattern that she had developed, and the doubts about her competence seemed to have disappeared from her narrative. Jessica did not once refer to issues of competence during her fourth interview, this being very different from her first three interviews.

A new found relaxed confidence was evident in the fourth interview with Jessica that took place one year after she started work in a beauty salon in which she had been open about her disability. Jessica had not been treated in the ways she feared she would when people discovered her psychiatric impairment. Significant to note was the fact that she wore a blouse that revealed a scar on her chest that she had been hiding up to this time.

Other participants seemed to share this experience. When the nature of impairments became known in the place of work, difficulties experienced became less diffuse. Chriselda, for example, could point to exact instances in which she felt she was being discriminated against. Such incidents would result in the anger she experienced. Her anger was focussed however, without causing the generalised discomfort and alienation Jessica seemed to experience while she worked without disclosing. Donovan and Sharon also attempted to work without disclosure before they altered their decision to disclose. Both these participants experienced a similar sense of being true to themselves and reduced diffuse anxiety that they previously experienced when they attempted to work without disclosing.

Conclusion

The issues presented in this chapter represented conscious or unconscious mechanisms or strategies that participants used to live with disability. Participants identified some of these issues themselves and were able to discuss the strategies as well as possible consequences. Other strategies were however not conscious and were understood from the interpretation of participants' life stories together with their behaviour and to some extent the discrepancies between those things they hoped to do and what they ended up doing.

Some of the strategies participants used were required to protect identity, whilst other strategies were about promoting participation in various occupations. In Chapter 8 the discussion will look at work as a health-giving phenomenon. It will show how participation in work assisted participants to re-build their lives and to promote positive identity construction.

Chapter 7: ACHIEVING WELLNESS THROUGH WORK

Introduction

If one accepts Baumeister's view that "the self is inferred from experiences" (Baumeister, 1986:14) it follows that experiences in work would have a direct impact on the self. Participants all recognised work as a mechanism through which they were able to meet their needs and as a goal that would assist in their self-development. However, they also gauged the value of their contribution and (in some instances) their wellness against their participation in work. Maintained involvement in work was for all participants their ultimate goal to work towards; reservations they might have had concerned their ability to obtain and maintain work. They understood, without reservation, that such a goal was the expectation of people around them as well. Participants did not doubt the value of work as a health-giving occupation and saw it as a mechanism through which they could meet a range of needs. In other words, work was seen as (1) a means through which better health could be achieved and (2) a goal that, once achieved, would signal the achievement of competence and good health to others.

In emphasising the value of work in this chapter, I am not disputing many well documented negative consequences of work on the health and/or wellness of workers. Participants' stories included examples the hardship they endured when participation in work caused unhappiness, high levels of stress and, in particular settings, ill-health. When, however, participants compared periods of no work with the hardship or boredom endured in less than ideal work situations, unemployment was considered the heavier burden.

Having a 'work vision' seemed to affect the ability of participants to work in positive ways. By work vision I mean the ability to perceive a future that involves participation in work. Participants with a future picture of themselves

as workers seemed to have increased confidence in their own abilities and seemed to invest more energy in constructing a path for themselves in the world of work. Similarly, having a work history seemed to be a positive influence on participants' ability to continue their work with particular employers. The difference between these two positive influences was that work vision was an internal process with motivational consequences. Having a work history was an external influence that led to better acceptance and accommodation in the work place. A strong relationship between these two influences was evident. Participants would develop a work vision based on previous and current work experiences. They would use examples of competence at work to confirm their own wellness and their ability to work. External influences, for example the expectations of family or judgements expressed about participants' competence however also impacted directly on work identity.

Achieving wellness through work will be described in much detail as a theme that emerged from the data. It should however be noted that, as a strategy with which to achieve wellness, participants did not find all work equally helpful. It seemed that the more participants held established elements of worker identity, the more they considered having work to be an integral part of their lives and the stronger their reliance on work to meet their needs, including identity needs.

This chapter discusses the improvement of wellness through work under the following themes: *Establishing and maintaining a worker identity*, *work well matched* and *work as a means of managing identity*.

7.1. Establishing and maintaining a worker identity

The extent to which participants' worker identity had been established was one of the most prominent influences that impacted on their decisions about

work, and the satisfaction they experienced with their current work or career seemed to be linked. Early on during analysis I realised that for some participants being a worker was an established part of their identity. Participants' identity formation seemed to incorporate their participation in work. Working was a way of life. The question was not whether to work or not, instead they focussed on how to obtain and maintain their participation in work.

Those participants who had been working prior to the first occurrence of psychiatric impairment seemed to be better able to maintain their involvement in work. This seemed to lead to them having developed a worker identity that became an integrated part of their overall identity. Participation in work became habituated into an integral routine of everyday life. These participants seemed to make every effort to maintain their existing work, or to find a new job when necessary. Those who were working did not want to contemplate a life without work, describing an existence without work in negative terms.

Suzaan seemed to have a well-established worker identity. She did not entertain thoughts of 'not going back to work' and viewed work as an obvious part of her daily routine.

"I never.. in all the time that I worked thought of giving up my job. I mean there were times I was in hospital, I just knew that when I get out of there I'm going back to work. And if I came out on the Friday.. that Monday I would be back at work". [Suzaan]

Being a worker formed part of Suzaan's identity construction. She spoke in ways that showed her identity as a worker to have been consolidated as an automatic part of her future.

"Yes because, I'm divorced and my children are grown and I cannot see myself ah.. doing anything else. Sitting around doing nothing. Like I said even if I had the money I wou- what do you do?.. with yourself all day. I think its important to be creative its- although I would love to do a beautician course and go into that field, I don't have the money right now. But.. I don't think its too late". [Suzaan]

This was not the same for all participants. In response to the first question asked during the first interview with Siphon, he gave a long account, detailing the experience of the onset of his psychiatric disability and the problems he experienced as a result of this psychiatric disability. At the end of his account, in the very last sentence, he mentioned that he was frustrated by his inability to work. However, the importance that he seemed to assign to concentration problems and his inability to sleep outweighed his frustrations about being unable to work. Having reflected on Siphon's experiences, I came to understand that he had a very tentative work identity, one that might not be of assistance to boost his confidence should he wish to find work.

With the exception of Galiel and George, participants all shared their doubts about the work they were doing at the time, or with the career they had chosen for themselves. Doubts about work fell into two distinct categories, depending on the extent to which participants had an established worker identity. Participants with a tentative worker identity had not made firm decisions about work participation in work or not. The tendency was to speak about future involvement in work using vague terms and not being sure about the types of work that would be suitable. Participants with a stronger worker identity knew that they wanted to work, but expressed doubts about current work or chosen career.

Three factors were identified to be interfering with participants' development of worker identity. Firstly, the absence of a prolonged experience of work

within a formal work-setting. Secondly, having to 'start all over again'²⁴ after a relapse became too demanding a task for participants who had lost their confidence. A macro environment characterised by high unemployment intensified the impact of these two factors. Thirdly, shifts in worker identity were brought about directly by symptoms associated with psychiatric impairment. Such shifts interfered not only with participants' ability to work uninterrupted, but also with choices made about work and satisfaction with a chosen career.

7.1.1. Opportunity to develop a worker identity

When participants first experienced psychiatric impairment before having had an opportunity to work, the development of a worker identity was extremely difficult. Sharon and Robert were at university when they first became ill; Andrew and Siphon were still at school. Donovan had only started work for the first time some weeks before he first became ill. Sharon, Andrew and Donovan slowly worked on development of worker identities within programmes designed for this purpose, specifically supported employment and TEP. During the course of this research Sharon and Andrew were in the process of developing worker identities while Donovan had achieved a permanent position and a well-established worker identity. Robert and Siphon were both participating in work-occupations, at Roseberry House and the Noluntu group respectively, without making their contributions formal in any way. Both participants were attending regularly and taking a leadership role.

²⁴ Participants experienced relapse as a major disruption; continuation of life after each relapse was experienced as a new 'episode'. Their use of language revealed the effort required e.g. 'picking up the pieces' 'rebuilding' or 'starting over'.

7.1.2. Starting again

Participants who had worked for some time, and who had developed a strong worker identity before becoming ill and losing their jobs seemed to be shaken by the fact that they were not then in a position to work. Finding a new job became an immediate focus, and the source of much anxiety. Being without work was something these participants did not contemplate. An obvious concern was to replace the income they no longer had, but the need to work went beyond meeting financial responsibilities.

The experiences of participants who lost their jobs as a result of having a psychiatric impairment seemed to be very different from those who could go back to doing the work they did before their illness. Those who returned to work seemed to operate from a position of strength when compared with participants who faced a life without the job when work used to be a part of their life. Having work waiting seemed to impact positively on both the experience of illness and the process of recovery. Getting back to work became the most important focus during the phase of recuperation, while also providing a sense of containment of symptoms.

Some participants did not seem to want to start over again when for one reason or another, mostly related to psychiatric disability, they found themselves unemployed. Picking up the pieces in order to start all over again was something that took courage, energy and that for some seemed to be more than they were able to cope with. Going back to a familiar work environment in which participants were known while they were well, served as a foundation from which they could continue their life. Participants without such a foundation found themselves in a position of having to start over again, re-building a life rather than continuing with life.

Whether or not participants were able to 'start all over again' related to their flexibility and attitude towards change. It seemed plausible that participants' flexibility in adaptation positively shaped their ability to maintain their involvement in work. The contrast between Galiel's point of view that was captured in the first quote below, with that of Robert in the second quote illustrates this point. Galiel, an expert at the work he did within the company, was prepared to be shifted into domains of work that required less skill in order to ensure continuation of work.

*"Ja, .. I had a very low self esteem.. at the time when I was ill, you know I felt like I couldn't go on, I couldn't.. I couldn't work I just felt so useless.. and then after I started therapy, and I was at home, and I started thinking **is this going to be my life, am I going to sit like this all my life, just sit?** I mean you just sit from the morning till the night, you get up, you do nothing, all you do is you sit around, you don't even help with the kids.. ..I think.. the time off from work made me realise how important work really is, and I think, that boosted my confidence to go back and you know, ..just to give it my all and.. ..cause I knew at the back of my mind, you know, I was.. at the stage when I was well again I became so worried because I thought.. my boss is paying me now, but he's not going to pay me for the rest of my life. And I have to, I knew that I had to get back to work.. no matter what happens, even if I had to go and do some other work, lighter work or.. something that took less concentration, maybe just a driver or something, you know.. delivery boy, a labourer or something, just.. you know, work for my family, for my children". [Galiel]*

Robert seemed less able to make adjustments in order to find work for himself outside Roseberry House. He was not considering work outside the domain of Law, his choice of career before he first experienced psychiatric impairment. Robert, who had completed a Bachelor in Arts degree, disregarded the qualification he had completed successfully. Instead, he persisted with the idea of completing his LLB degree before attempting to find

work. After 14 years, this goal did not seem attainable, not even to Robert. He also opted not to join the TEP programme within Roseberry House.

"Yes I think so. I'm familiar with Roseberry House now.. , and if I'm to break new ground and go into unfamiliar territory, then it's got to be slow, it's got to be slow. .. that's.. I'm scared, I'm scared of going into unfamiliar territory.. because .. I don't want to.. fail.. I don't want to.. ..have my confidence knocked once again, you know, as far as work goes and.. .. familiar.. I'd say Roseberry House is familiar, ja.. ..but with also lacking, lacking in work experience.. is something.. thatif I had to apply for a, for a job.. then that would be.. moving away from Roseberry House and going into meeting new people- that's a big thing..

When I was Head Boy at High School, matric, played provincial soccer, and I've always been a "aim high" sort of chap. It doesn't just have to be the degree that can give me pride, there's other things that I could also do that I could feel proud of. I'm proud of this place, I'm proud of Roseberry House. So it looks like I'm getting satisfaction and fulfilment out of something different to full-time UCT, I'm getting self respect. I'm proud of the work I do here, the work I'm being taught. I'm proud of Roseberry House. So maybe I'm moving into a new area now. Given time, maybe, I won't be so obsessed with this whole law business you know. If I can make some money, if I can make a living, somehow, through Roseberry House, and what the next step is, if I can make a living, I must just go with the flow". [Robert]

7.1.3. Accommodating shifts

The often tentative identity constructions of participants were linked not only to fluctuations in their sense of identity (mostly linked directly to their psychiatric impairment), but also to constructions of identity, competence and suitability. Emotional discomfort, together with a sense of alienation, was experienced in varying degrees depending on fluctuations experienced from within or from the external environment. Degrees of discomfort depended on

participants' ability to 'hold' uncertainty, discomfort and alienation for prolonged periods of time. During such times participants doubted their decisions about work and their suitability to work. Doubts would differ in severity, from a tendency to rethink decisions to being unable to make decisions. For this reason participants often seemed ambivalent about their decisions about work.

Jessica's uncertainty about being a beauty therapist is illustrated by the following three quotes taken from the same interview. The interview took place days after Jessica had resigned from an upmarket beauty salon in which she had been working to start her own business from home. Her own business was not succeeding, and when the owner of the salon she had been working for approached her to do locum work for a period of time, Jessica agreed.

"...I said I'd never.. don't ever use the word never, I chose the word never, I never want to go back to beauty therapy again because.. it's about touching people to make them happy. But, too many people have told me about my hands, that I have to use them in my work..

So I knew I had the job.. so, but I think its been a very stretching, excellent-excellent oppor.. I really want to carry on with beauty therapy now. I would like to work with a psychologist one day...

I think I'm a con-artist that's what I feel, I feel as if I'm not really a beauty therapist-like smart but feeling dumb.. it the same thing I suppose if feel.. ..but yet, it's a gift I mean I really, really have a gift I mean, I've watched people when I massage them.. how it affects them.. it's wonderful, wonderful stuff". [Jessica]

Jessica's ambivalence might have been more pronounced because of the uncertainty surrounding her work at the time of the interview. Examining all the interviews with Jessica over a period of two years, it became clear that

her ambivalence about her chosen career was linked to her mood state. Being a beauty therapist seemed to have more appeal when she was experiencing an elevated mood state. She would talk about beauty therapy being her 'calling' and shared her future vision in which she was working in conjunction with a psychologist to achieve wellness for their clients. In a subsequent interview Jessica's mood state was lower, and being a beauty therapist had lost its appeal. Jessica was finding it difficult to capture a career vision for the future. She certainly did not consider beauty therapy as an ideal career for the future. Much changed later on for Jessica who returned to doing beauty therapy, this time having disclosed her psychiatric disability. She felt consistently happy about her chosen career and worked in the same salon for longer than a year.

Suzaan had a well established worker identity. She had been working for the same company for 22 years when I met her. She held various positions in the company as she worked herself up to a position 'in Head Office' that she held when I met her. She shared her dream of becoming a beauty therapist with me during the first interview. For Suzaan, it seemed, this dream became more of an issue when she experienced manic episodes. During these episodes she spoke about wanting to undergo training as a beauty therapist in order to change her career. The only reason she gave for not changing her career was her inability to afford the training.

For Jessica and Suzaan their satisfaction with their chosen careers was directly linked to their illness experience. Galiel and George similarly came to view their jobs differently when they were experiencing paranoid ideation in the work place. Both these participants were particularly satisfied with the work they were doing at the times of the interview, but found it an unsafe place to be when they became suspicious of people at work due to symptoms associated with their illness.

It is important to note that the shifts being described here could potentially derail participants from being able to work successfully. Christo 'resigned' from work during his first hypo-manic episode. Over-confidence, linked to grandiose ideation he had at the time, informed his decision to start his own business. The shift in Christo's mood state effectively ended his seven-year work history with the company he was working for.

The key to maintained involvement in work related to the capacity of the individual, as well as the work environment, to 'hold' negative feelings or ambivalence that interferes with work satisfaction. The ability to continue work despite fluctuating levels of satisfaction was a crucial, albeit obvious, influence that maintained and threatened involvement in work.

7.1.4. Decisions about disclosure

In the years that I've worked in psychiatry settings the issue of disclosure is one that was always at the forefront when people with psychiatric disability prepare to re-enter their lives after treatment. Information is not available to guide decisions about disclosure.

When participants, or their families, anticipate discrimination they often choose not to disclose their disability status. In the past, the only risk associated with such a decision was that an unexpected relapse might lead to being 'caught out' as having an undisclosed impairment. However, since the promulgation of new labour legislation in South Africa particular disclosure could be beneficial; reasonable accommodation is one example of such benefit. Disabled people who alert employers to the fact that they have a disability during the appointment phase of starting a new job are eligible for reasonable accommodation. Disclosure would also offer protection against dismissal on the grounds of having a disability. Reasonable accommodation in the workplace, support mechanisms, protection against unfair dismissal due

to illness and education focussed on the removal of attitudinal barriers in the workplace are strategies that can only be implemented once participants disclose their disability and nature of their impairment. The decision to disclose, as well as when to disclose, could therefore have a major impact on a disabled worker's ability to secure and maintain work.

Disclosure also seemed to influence the level of integration experienced by participants in the workplace. Most people with psychiatric disability, their families and service providers operate on the assumption that disclosure of psychiatric impairment will lead to alienation in the workplace. However, participants in this study experienced the opposite. Jessica's story best illustrates the impact of disclosure on ability to participate at work.

At the time of our first interview Jessica was 43 years old. She had had an erratic work-life, moving from one job to another with frequent career shifts. Jessica would stay in the same job for three months to a year. She would then choose to leave, often without an obvious reason. Jessica never disclosed her psychiatric disability to employers or co-workers. Strong interpersonal skills and a seemingly outgoing nature allowed her to find work easily. Even though her work-history was fragmented, Jessica gave assurances that she was a good worker. Several incidents, one being that she was approached by a previous employer to locum at a beauty salon weeks after resignation, at almost double the salary she earned while working there, provided evidence for the fact that she was indeed a good worker. It became clear that, for Jessica, everyday participation in work was demanding to such an extent that she would leave as soon as an opportunity arose for her to do so without causing too much disruption at work. Jessica found the effort to sustain work sufficiently difficult that she needed to 'drop out' when a good opportunity arose. In one of the interviews she spoke about leaving one of her jobs as "a door opening", allowing her to leave.

This all changed when Jessica was approached to work in a beauty salon for an employer with Parkinson's disease. At the onset her new employer explained to Jessica that she could no longer manage her clients due to deterioration of her physical abilities and endurance. She focussed on the management of the business. Jessica, impressed by the openness of her new employer, disclosed her own disability status for the first time. A year later she was still working at the same salon. She had changed her attitude about disclosing her illness and explained how this new attitude had freed her to do things differently. Small accommodations, for example the fact that she was not expected to constantly play background music, alleviated stressful irritations that previously made work difficult. Constant music had in the past led to her feeling over-stimulated and irritated, in turn causing frustration and feeling overwhelmed. Without disclosure, Jessica would not have been able to ask for the accommodations that now seemed to make a big difference in her ability to work.

The acceptance that came with disclosure, together with being in a position to make needs for accommodation known, made all the difference. She was developing new confidence in her ability to work. Jessica disclosed not only to her employer, but also to co-workers and some of her regular clients. The result was that she experienced improved interpersonal relationships and acceptance and greatly reduced feelings of alienation in the workplace.

When participants first experienced psychiatric impairment while already employed, they obviously did not have a choice whether to disclose or not. Chriselda and Dorothy found themselves in such a situation. Their experiences were different in that Dorothy found that the knowledge employers and co-workers had positively impacted on her relationships at work, and her ability to speak freely about matters associated with her impairment as well as those that were not. Chriselda experienced similar acceptance at first, but soon found that employers no longer seemed to trust her. Her work as a fashion designer was shaped to increase her involvement

in administrative and technical tasks, such as development of textiles, while responsibilities that involved relating with clients or the public were given to co-workers. Chriselda's disappointment with this state of affairs made her re-think her work in that particular setting; she considered leaving in order to start her own business.

Disclosure emerged as a prominent influence that clearly impacted on participants' ability to work. Positive spin-offs that came with disclosure were clearly evident in the experiences of most participants. Chriselda and Christo were the exceptions in this regard. The issue of disclosure is a crucial one and it will be explored further in chapter 8.

7.2. Work well matched

When there was a fit between the needs and interests of participants and the work they were doing, they seemed to participate with ease and find work a pleasure. The creation of a good fit between work and the abilities and interests of workers is something that is not new to occupational therapists. The positive impact of having work that matched the interests and abilities of participants was clearly illustrated in the study. Interviews with participants who enjoyed what they were doing and who felt comfortable and competent revealed their confidence that the future, with work, would be positive. The focus of concerns raised seemed to be on the management of their psychiatric impairment rather than on issues related to work. Work served as a stabilising influence that made the future seem more manageable. Concerns seemed to be with possible ways in which psychiatric impairment could interfere with their future ability to work.

George was a particular example of somebody who was ideally suited to the work he was doing.

"Nee, nee dis baie, dis a baie lekker werk. Dis baie lekker werk. Jy weet die middelde is so.. baie, baie Desember-maande, dan is die swaar werk. Gewoonlik is daar so drie man.. jy werk nie te swaar nie, behalwe einde van die maande, dan steek die werk mos nou op- dan vat die customers nou mos klomp goete en so aan.. nee mens moet maar net sweet en kom. Daar wat hulle jou aflaai en dan eers ry, dan kom hulle weer terug en laai jou op en so aan, so aan, so aan. As ons nou klaar is, dan kom ons nou mos terug".
[George]

No, no the work is great, it is great work. It is a great work. You know the average is.. many, many.. the months of December, the work is heavy. Usually there are three men.. the work is not too heavy, except for month-ends, then the work tends to be more- customers buy lots of stuff.. no, nothing to be done but hard work. First we download and then leave for the next place, then return again to load our stuff and so we continue, until we finished. When we've finished, we return.

The motivational influence of participation in work that was well suited to the needs and abilities of participants was obvious. Furthermore, it provided containment to participants who relied on having work as a foundation from which they were able to confront the uncertainty that was associated with psychiatric impairment.

7.2.1. Accommodations at work

When the environment at work or the systems and procedures that are used to shape work behaviour are not naturally a good match for the skills and abilities of people with disability, accommodations can be made to improve the goodness of fit. Such accommodations, according to the South African Code of Good Practice (2000) should not interfere with the expectation that the employee should competently fulfil the requirements of the job.

When participants were asked about accommodation, all participants singled out the attitudes of co-workers towards them as disabled people as their main concern. Obvious accommodations might have increased the discomfort that many participants were experiencing in their quest to prove to co-workers that they were competent and worthy role players in the workplace. This might explain the tendency by participants to welcome the concept of reasonable accommodation as a strategy to assist other people with disability to participate in work, but at the same time insisting that they themselves did not need such accommodations.

Participants spoke about adaptations that had been made in their environments, without necessarily recognising these as reasonable accommodation, for example being allowed more than the allocated number of sick leave days. Such adaptations improved the fit between the participants' abilities and the work they were expected to do, in the following ways.

- **Assistance with management of impairment:** Dorothy, George and Chriselda became ill, for the first time, while they were at work. Their employers were involved to a larger or a lesser degree in the management of their illness. Assistance was given with access to the services they needed for the management of their impairment. In George's case, co-workers picked up that he was not well. George, who was experiencing paranoid ideation, contributed the source of the problem to the fact that his co-workers were talking about him behind his back. When he became violent at work, his employer sought help on his behalf. Dorothy received similar support when she started behaving inappropriately at work. Her supervisor established contact with her mother and set up a meeting to discuss concerns and to discuss possible steps to be taken.

- **Time for follow up appointments:** Participants were all given time-off from work to attend follow-up appointments. Chriselda was also given one afternoon per week to attend a drumming workshop that she found to be beneficial.
- **Flexible work hours:** Sharon worked for four hours per day and four days per week. This was done to prevent fatigue that in turn leads to her hallucinations being much worse. Similarly, Jessica negotiated to work for four full days during the week and a half-day on Saturdays. This arrangement suited her well and seemed to prevent over-stimulation and uncomfortably high levels of anxiety that made it difficult for her to maintain employment previously.
- **Flexible sick leave benefits:** Employers made allowance for those participants who needed more than the allocated number of days for hospitalisation and subsequent recuperation. Chriselda had to take unpaid leave to cover her period of hospitalisation, but George, Galiel, Dorothy and Suzaan received full benefits during these times. Not all participants needed prolonged sick leave; Donovan, Jessica, Malixoli and Sharon were also employed but did not need this accommodation. They had not had relapses that required prolonged hospitalisation.
- **Gradual entry back into work:** Some participants needed to ease back into their work after a relapse. Galiel and Dorothy were both given the opportunity of initially working less hours which they gradually increased until they were working full-time again. Galiel, who worked on high-speed machines as a specialist fitter and turner, was given alternative jobs to do for a period of time. He did this until he felt confident enough to start doing his original work again. When he returned to work, it was for four hours per day. His work hours were gradually increased to allow him to ease back into working full time over a three-month period.

- **Educating co-workers about psychiatric impairments:**

Exploration of reasonable accommodation with participants inevitably led to participants sharing their view that all they needed was to be treated fairly. Education of co-workers was something that participants identified as a need. They would either explain how they themselves were attempting to explain their psychiatric impairment to co-workers, or they would share their conclusion that psychiatric impairment could not be understood by people who have not experienced it. Not all participants directly identified the need for education of co-workers, but they expressed their wish for their illness to be better understood.

"I've been working for some time. I think for me the biggest problem I actually had was.. um.. or even still is.. um.. people's attitudes. Um.. and also basically ignorance when it comes to mental illness.. lots of people think, or have this idea that.. um.. a person with mental illness is.. um.. let's say.. um you're crazy, or you're mad.. um.. and they somehow link that with people who have either got chronic.. um.. um.. mental disorder, or.. um.. even the criminally insane, and they look more at the.. um.. that negative side of things; and.. um.. it seems to me.. um.. like a blanket attitude that they have towards you.. um.. the stigma is still out there and I think some of the employers, actually for me, as far as my experience is.. um.. lots of them are still ignorant when it comes to mental illness.. and.. um.. basically.. basically they see you more as a danger than an advantage to them um.. in the work place". [Donovan]

7.2.2. Supported employment

Through supported employment disabled people are placed in jobs that are well suited to their abilities and interests. Sharon was the one participant in this study who was in a supported employment programme. Before entering into supported employment, Sharon unsuccessfully attempted to find and

maintain employment on her own. She was living with active symptoms associated with paranoid schizophrenia that never completely disappeared. Her illness, together with the numerous barriers she faced, led to prolonged periods of unemployment. Through this programme she was given an opportunity to participate in a real job in the open labour market. Sharon explained her work needs in the following way

I did ask, I said I would like to sit down, I would like to be out of the mainstream and please, I don't want to speak on the telephone, or handle money, because I still have a problem counting, I can't count very well. And I.. ..I don't mind talking to people, but I don't.. I don't want a desk job.

Sharon found work in a library, with the assistance of an occupational therapist who co-ordinated the Supported Employment programme. She was able to fulfil the requirements of the job, and was paid accordingly. On-going support was provided by the previously mentioned occupational therapist.

For Sharon, supported employment seemed to bring together the best of both worlds, work that is well suited with accommodations already made.

7.2.3. The Transitional Employment Programme

The Transitional Employment Programme (TEP) emerged as a strong enabling mechanism for people with psychiatric disability to develop a worker identity and maintain work in the open labour market. The TEP is different from supported employment in a number of ways. Work obtained through a supported employment programme is held by the disabled person and is permanent. Within the TEP jobs are held by Roseberry House and members are given an opportunity to work in a particular job for three months at a time. Members who join the TEP would usually rotate through a number of three-month placements. Another difference is the level of support. Within a supported employment programme the disabled person in that post carries

the responsibility for the job. Within the TEP, members can rely on other members of Roseberry House to work on days that they themselves are not able to work.

Andrew, one of the participants who had experienced unsuccessful attempts at work without formal support, repeatedly highlighted the value of being in the TEP:

"...I went to work every.. day, I got up. I had support, that was the main thing, and we were told if you're not feeling well, you can stay at home. But it was not strict actually it was just we learn to work and it's normal life, just it was a lot of support at Roseberry House.."

On my life.. it's changed my whole life, I wouldn't have been where I am today.. Roseberry House at least have helped me to get somewhere, where.. where I'm satisfied where I am, look I.. I.. don't even know if I need to study, I never knew life could be this great, I thought my life was over when I had the illness, I'm not joking, I'm serious. Ja.

It's starting all over.. I've been born again, honestly. I thought my life was over. And when I had the hallucinations, they knew I had it at Roseberry House.. they just said to me "listen, go for it". I told them I'm scared, whatever, they told me go for it, they told me how to deal with the situation, and my hallucinations stopped at work.. honest, it's good man". [Andrew]

The knowledge that work was safeguarded in the event of symptoms becoming worse, or even relapse was invaluable. This seemed to be a key ingredient in the success of the TEP. Donovan talked about the impact of knowing that his job would be safe in the excerpt below.

But , just the fact that I knew that if there was something to go wrong, I'm not gonna lose my job and things like that. Whereas before, that's usually what would happen, like I mean I'd crack up and everything and I'd lose a good job and stuff like that. And , there was nothing, there was no support or

nothing backing me up and at the end of the day, then I have to start at, right at the beginning again, and it's it really I mean it breaks you down and you like really feel, is it like worth it even, sometimes, is it all the effort I put in and whatever it's, it's at the end of the day, if I fall flat on my face, again, then like you know , once again, there'll be no-one for me.

Donovan described his job as being stressful, demanding flexibility and the ability to take on more than your own responsibilities. He also highlighted the need for attention to detail. He spoke about his job with obvious pride, highlighting his own role in making his permanent employment a reality. For Donovan, Roseberry House and the TEP seemed to function as a 'safety net' when he needed it. He explained that he, unlike some of others on TEP, never needed Roseberry House staff to help him with his work physically. Instead, he seemed to benefit from knowing that they would be available in case he needed their assistance. This kept him going independently, unlike previous attempts, when he worked without a 'safety net'.

The TEP provided participants with a testing ground. They were able to test their own competence against the demands of a real job in the open labour market. Success within the TEP instilled confidence in their ability to work.

7.2.4. Support at work

Support provided at work emerged as a powerful positive influence that impacted positively on participants' ability to work successfully. Participants were however quick to insist that they did not ask for preferential treatment. Special treatment caused discomfort and irritation and was not considered to be helpful. Support, on the other hand was singly mentioned most often as an influence that helped participants initiate and maintain work. Support, for participants, meant a combination of having knowledge of their impairment, having an appreciation of the difficulties that result from having the impairment and being accepting.

Donovan obtained full-time permanent employment in a large insurance company after successful completion of a six-month TEP placement. Donovan insisted that he did not want or need any special assistance. He did however have strong views regarding the lack of knowledge regarding psychiatric impairment displayed by his co-workers. Donovan spoke about his need to be treated with consideration and respect; the same respect people without disability have for one another.

"And that I'm not.. I'm not just existing or.. or.. um.. that I'm living in the full sense of the word. Never mind any of the obstacles, the obstacles that that we have, we deal with in our way and we don't feel, I mean I don't feel that.. um.. the employer.. um.. or even your colleagues and so on, in your workplace, need to treat you any differently.. um.. they need to give you the opportunities and.. and.. the exact same chances that they have to advance themselves, but naturally their approach towards you.. and.. um.. the attitudes, and the way that they do things, basically they just need to show you the same kind of respect, the same kind of courtesy, and.. um also.. um.. um.. for me also, the biggest thing is, of course, the stigma attached to mental illness". [Donovan]

Donovan's life story showed that he had had a rich experience of work with psychiatric disability. He started work at a young age, before having a psychiatric impairment. After losing his first job due to illness, he struggled for years to obtain work. During this stage, in which he was also mis-diagnosed, he made numerous attempts to work, each lasting for a few weeks to a couple of months. This changed when he was correctly diagnosed and referred to Roseberry House where he joined the TEP.

It was particularly the support built into being a member of the TEP that seemed to be an essential ingredient for success for those participants who were members. Participants with employers who acted in ways that communicated their support were greatly encouraged to continue their

participation in work. The element that preserved work seemed to be that participants were assured that they would not lose their jobs as a result of illness. Employers' obvious power to ensure that jobs would be safe is illustrated in Galiel's quote below.

"... my boss, he was wonderful he also supported me, [name of occupational therapist] was in contact with him all the time, my wife used to be in contact with him. He just told my wife.. look, um.. she mustn't worry, I mustn't worry.. um.. once I'm back on my feet I must know I must come back, I have my job in my place. He employed someone else in my place, because we're a small company, but.. ..also just until I got back, until I was fit again to go back, then I had my job back, so.. I'm very grateful for that, that was also a very big help for me, knowing that I'm ill, I'm at home now, but at least I know.. that once things change for better I will be able to go into a job again". [Galiel]

Behaviour considered helpful from co-workers contained the essential element of fairness. This was something that all participants agreed on. Many examples were given of instances in which participants felt they were treated fairly. They often equated being treated fairly to the way their colleagues without disability were treated.

Participants who were open and comfortable about their disability status, thereby allowing support from others, seemed to benefit greatly from such a situation.

7.3. Work as a means of managing identity

Through their engagement with aspects of work, participants were able to meet some of their identity needs. Work became a mechanism used by participants to re-build their confidence and to make them feel worthy. Work

was used by participants to gauge their own wellness; being able to work was equated with being well.

7.3.1. Validation of wellness and worth

Work seemed to be the one measure of competence and worth that was external to themselves and their own behaviour. Furthermore, being able to work served as a *public* statement to people with psychiatric disability themselves and to society in general that indicated wellness and competence. Many of the stereotypes held in South African society about people with psychiatric disability culminate in a view that those with psychiatric disability are not able to work. This view often goes unchallenged, and people with psychiatric disability themselves buy into it. Against this backdrop, being able to work made a strong statement about participants' worth and ability. Some participants surprised themselves that they were in fact able to maintain work. Others were confident about their ability to work, and used it to challenge perceptions of society at large that they were somehow less able than non-disabled people.

Three excerpts from an interview with Sharon demonstrate the complex interplay of benefits to be had from employment. A range of different needs; financial gain, self-esteem, belonging, acceptance and the need to care for others were met by her involvement in work.

"You know, even my physical appearance has changed. I now have money to buy suitable clothing, and for my husband and my daughter. So.. .. this has helped so much in my life, being a useful, productive member of society.

But now, like I'm getting into routine, because I can see .. I don't .. when I was ill I'd lie in bed all day, and just cry and scream, and drink 16 cups of tea, and you know, I was a basket case. So I'm trying actually to re-structure my life. As my mind is becoming restructured through um.. routine and

discipline at work, everything has to be filed consecutively and numerically, so it's a very good exercise for the mind...

But like, I still make mistakes, not at work but just generally, maybe I don't dress properly, or my hair style is inappropriate, you know, I would like somehow rehabilitating myself to dress properly for work and you know, so that I don't sit there and look like, you know the village idiot in an environment that is quite up-market, because it's a very nice library, you know, it's very smart". [Sharon]

Even when participants did not enjoy the work they were doing, they recognised value in being in a position to work.

"I dread having to go to work in the morning, but when I get there and um.. working with people, interacting with people, and working together with other people, it um.. um.. it's sort of um.. .. um it's enjoyable to feel that sense of self". [Chriselda]

Dorothy explained how, when she was having a bad day, she would stop and say to herself: "I am working, therefore I am fine. I am not crazy, crazy people cannot work". She elaborated by saying that while she arrived at work on time, stacked the shelves as required and assisted customers when they asked for her assistance, she went home in the evenings knowing that she was well.

7.3.2. Integration through interaction and contribution

Having a psychiatric disability is something that has an isolating effect on people. Participants' use of language, such as the way in which they spoke about 'normal' people as being different and separate from themselves, as well as their stories, demonstrated that they did not experience themselves as being integrated into mainstream society. The experience of being different

and apart from people without psychiatric disability was also evident in the narratives of those participants who did not mention discrimination and stigmatisation directly. Being lonely seemed to be an expected part of everyday life for many of the participants.

A by-product of working is the interaction with co-workers. Participants that were working all spoke about relationships at work. These were not always comfortable, but the participants' need to demonstrate their competence to co-workers was evident in all their narratives. This need was closely aligned to their need to prove their competence to themselves. Being able to work, and showing co-workers that they were able to work contributed to participants' confirmation of their own wellness.

For Siphon, working as part of a group allowed him to experience a sense of community. This is something that he was not able to experience in other contexts. Siphon not only formed part of the group, he took a leadership role within the group.

"The people I work with are the people that I know. When I am amongst them I don't have the feeling that I am sick although I know I am. So that is why I like being here". [Siphon]

Andrew explained how being a worker set him apart from those with mental illness and grouped him with 'normal people'. The guilt he so obviously felt at making these comments might be seen to indicate the shame he himself felt when he was a non-worker.

"Ja it changes me, it changes how I meet new people and working with.. working with new people, I've got the confidence to speak to my friends at work, I don't have to.. it doesn't have to be a person who has a mental illness, ..'cause I feel different now, I feel I'm learning, to be like a normal person because I'm round normal people. On TEP that started, I felt.. .. I wouldn't say, I shouldn't say this but.. it's a bad thing to say, but I have to

say it to the research.. you feel normal when you have to work, because you can come to Roseberry House, I shouldn't say this.. ..but I will say it, .. Youfeel a bit better 'cause you feel different from the others who's not working, because they have a mental illness and you feel so confident coming from work, but it's.. it's a bad thing because you are more positive than them. They are feeling a lot of stress, they are stuck with a lot of stigma. Being around normal people, for more than four, for more than three hours, two hours, makes you so called "normal" in your mind although you've got a chemical imbalance, whatever, so it helps a lot with a mental illness. I even used to think this is part of my therapy for schizophrenia, but eventually the delusion went away and I realised no, it's the real thing, it's working".
[Andrew]

7.4. Motivation for, and obstacles to, work

Certain external influences affected participants' participation in work. While these influences were not always comfortable for participants to have to endure, they motivated participants to attempt work.

7.4.1. To earn money

The main factor pressing for work was the need to earn money. Even when work situations were less than ideal, participants favoured work above periods of no-work. This was in part due to the need to earn an income. In the excerpt below Chriselda shared her experience of work. Conflicting feelings and difficult decisions are illustrated:

"Ja, sort of um.. productive can um sort of ..um.. the more you're capable of working um.. it means.. to you it means um.. .. um.. you sort of fit in .. in society. And um.. .. um I suppose you, you're accepted by society, if you work. .. I dread having to go to work in the morning, but when I get there and .. working with people, interacting with people, and working together

with other people, it it's sort of it's enjoyable to feel that sense of self. ...the job that I'm doing now, and the company that I have to go to work for, it's like .. every morning it's .. 'do I have to go to this place', and it's .. 'I have to go because I have to eat, I have debts to pay, I've got bills to pay'.. that kind of thing. And also the .. sort of .. being glad that I do have a job. And it's , some days it really gets me down, I feel really frustrated, in the work that I'm doing..” [Chriselda]

Many other similar quotes could be given to illustrate the multi-dimensional value of work. The quote illustrates the fact that work brought an income. Financial gain then led directly and indirectly to participants' ability to have other needs met.

The quotation emphasises the need to work and the reason for doing so, but contrasts that with how difficult it is to keep it up. It shows realistically how work is of benefit, whilst it is not always easy for people with psychiatric disability to succeed. Other participants spoke about how difficult it can be to maintain work. However, participants' narratives revealed that episodes of unemployment were found to be even more distressing than difficult experiences at work.

7.4.2. Responsibility for family

Family responsibility pressed for work in much the same way as the need to earn an income did. However, the quality of the commitment was different. Caring for family implied taking responsibility for the well-being of others, and also implied fulfilling socially constructed roles that served as a validation of ability. Suzaan is talking about her daughter in the excerpt below.

"I think it's .. in my case, I've got a responsibility.. the main thing for the past.. the first three years, when I had the first three breakdowns was.. my daughter. I knew.. she came first. That is why I pushed myself. If she was..

if she was not living with me.. and working.. I wouldn't have done it. I might not have done it.. for myself, but I did it.. because I knew that she had to finish her college and I had to push myself to go work. And.. in a sense that was like a.. like a.. base, now I would do it for myself. Because she's now finished with her college and she's working.. so I, I.. it was a good push you know what I'm saying? [Suzaan]

7.5. Obstacles encountered

Some participants did experience the negative consequences of stigma that so many disabled people anticipate and fear. The negative consequences experienced by participants in this study was characterised by unfair approaches to workers with psychiatric impairment, specifically unfair dismissal and withholding of promotion. The devastating consequences of these practices were far-reaching. Participants to whom this happened may have been particularly disconcerted by these behaviours because they had well established worker identities. Facing a process of recuperation, without the foundation provided by having a job, caused major disruption and anxiety. Neither did they have a reasonable expectation that they would find work in the future. Participants who had worked for a number of years come to rely on a steady income to maintain a lifestyle that they had grown accustomed to. Without work as a base on which to build their future, the unpredictability of psychiatric impairment seemed more threatening.

7.5.1. Unfair dismissal

Christo was the one participant who lost his job because of becoming ill. His first experience of bipolar mood disorder started with him becoming manic. In the time leading up to his illness people around him did not recognise his behaviour as symptoms associated with illness. Instead, they judged his behaviour without taking cognisance of the fact that he was ill.

"I worked for them until.. the end of '99.. huh [said in a way one says it when you ask a question] no.. the end of 2000.. for six years.. ..and then I had my breakdown. What actually happened was, when, when I approached them I, I approached then and said look.. I'd like to start my own company, but.. can I carry on working.. with you guys till.. I've sorted- got my stuff sorted out.. and they said ja. And then.. I know.. that an incident happened because I was neglecting my work and that.. my mind was elsewhere.. because I wasn't well.. an incident happened.. .. there was a discussion over the phone.. where I was a little too aggressive, okay.. ..and I think that was kind of the, the decider that, that they were just gonna kick me out in the end.. leave me out to dry.. so to speak.. .. so their whole story changed.. [after discharge] that I came to them and I resigned. That's what they said.. what they said when I first went to the CCMA.. and they said.. too late".
[Christo]

Nicolas, who was working for a very supportive employer spoke about an earlier experience where he was asked to leave the company he had been working for many years. This was a direct consequence of Nicolas needing a second admission for the treatment of depression after a suicide attempt.

Both Nicolas and Christo had received promotions more or less a year before they lost their respective jobs. This indicates good performance, thereby suggesting that the dismissals were brought about by psychiatric disability rather than poor performance.

7.5.2. Promotion withheld

Chriselda had been working for a new company as a junior fashion designer for almost a year. During this time, she worked under the guidance of a designer who was expected to train her. This designer was close to retirement, Chriselda would then be promoted to the position of designer.

At our first interview, Chriselda indicated that her life in general and at work seemed to have changed for the better after hospitalization. She experienced an improved sense of self and was more assertive. She had terminated a seven-year relationship that she labelled as being a "dead end" relationship. She also was able to speak to her boss about problems she was experiencing at work. Chriselda felt good about the fact that she had been able to speak up. She contrasted this with her tendency to "bottle up everything". Chriselda explained the frustrations she used to have as follows:

"I was feeling very frustrated because I was hired as a junior designer-clothing designer, and the person I was hired to be a junior with, the person who was meant to train me as a junior assistant and a junior buyer.. she was using me as a secretary. She would tell me to go to reception, 'go fetch this'.. , 'just type this out for me quickly', 'can you just source this elastic'. The stuff that I was meant to be doing, was, like liaising with the clients, getting to know the clients, stuff like that". [Chriselda]

Chriselda was proud of the fact that she was able to discuss these concerns with her boss for the first time after returning to work from having been hospitalised. She was looking forward to taking over the responsibilities of senior fashion designer at the end of the month.

The mood of our second interview was very different from the first one. Chriselda was disillusioned by the consequences of having a psychiatric impairment on her work. The promotion she was hoping for had been withheld and two new designers had been appointed instead. The new designers had been appointed on the understanding that the clients would be divided equally amongst the three of them. Once appointed, it became clear that Chriselda was expected to take responsibility for the technical and administrative tasks only. Clients were divided equally between the two new designers. While Chriselda's new found sense of identity remained intact, she discovered that she was being marginalized at work.

"Yes, I am, because it's ...um... the big bosses idea is that I should cover all the technical aspects of everything in the house, I should...um...um...the new designers for...um... they will do liaise with clients, they'll be creating the garments for the clients, what the clients want, and then ..um.. I have to run around and get the samples, get the yarns, like do all the dirty work basically, and it's..... it's.. not on you know, this is.. this is not what I want to do. I don't want to be somebody's lackey.

"Well, yes, in the sense that things are not going according to plan...sort of feeling helpless and frustrated...and um, going to have to find a new job and the job market the way it is, and the sort of.. the.. I feel as like I'm just stuck.. and that kind of thing. And I can always.. I can stay in this job and know it will take me nowhere and I will know I will get a monthly salary.. and.. but having no job satisfaction, will be, you know, it will break me eventually, and.. .. ja.. this sort of.. it's.. it's not gonna.. these people are not gonna (cannot hear) these people are not gonna change overnight and I suppose they're very.. what is it.. they're not willing to.. .. you know sort of this customer liaison (cannot hear) somebody who's been in a mental institute.. and I suppose it's just ignorance.. and there's nothing I can do they've got their set opinion now.. and you know, so be it, it's time to move on". [Chriselda]

Chriselda resented these events, she felt humiliated and betrayed by her boss. By our third, and last, interview Chriselda had made the decision to use her current work as a springboard from which to develop her own business or find other employment. She had, to some extent, made peace with her new role in the company and was using the opportunity to her advantage until such time as she would make the decision to leave for something better.

Conclusion

This is the last chapter in which findings are presented. It has focussed more specifically on work as a mechanism through which wellness could be restored. The essence of the chapter is that participation in work is what seems to improve the ability and possibility of people with psychiatric disabilities working. The importance of work in lives of participants was clearly evident from interviews with all participants. The life stories of participants who worked and those who did not work equally demonstrated the potential of work to facilitate health and wellness. Some of the issues presented here will be summarised and considered in more depth in Chapter 8.

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Chapter 8: DISCUSSION

Introduction

In this chapter conceptions of identity will firstly be examined in order to illustrate a move away from the idea that participants have a single and 'stable' identity. Instead it will be argued that identities emerge in response to particular contextual demands and in relation to conditions of identity that, in the case of the participants, included the impact of living with a psychiatric impairment. The conceptual frameworks that underpin these positions will be explored. Secondly, a model that was developed from the data to explain the influences that hindered or promoted participation in work, will be introduced. The concepts depicted in the model will be presented and illustrated with the life stories of several participants. Finally, issues of service delivery and the implications for the occupational therapy profession will be considered.

Section 8A: Identities, restriction and participation

When I first began this study I believed the notion of a 'stable' identity desirable and that it would provide continuity in people's lives. This initially led to my use of Baumeister's work as a framework within which to understand and present the findings obtained in the study. Final steps in analysis and interpretation (formal analysis), however, pointed to the need for a conceptual framework that did not give prominence to the necessity of a stable identity as being foundational for other functions of identity.

8A.1. Stable identity?

Life with a psychiatric impairment resulted in repeated experiences of disruption or 'destabilisation' in accordance with Baumeister's description of

the term²⁵. Most of these experiences were associated, directly or indirectly, with psychiatric impairment. The unity in identity was disrupted most significantly by the first occurrence of psychiatric impairment, but also with each subsequent relapse. These instances of destabilisation resulted in distress and anxiety on the part of participants and led to an anticipation of future relapse that further prevented their experience of unity in identity construction. This prevention of relapse might be said to have been the most significant source of disruption; participants were continuously scrutinising every domain of their lives for indicators that relapse might be imminent. When participants thought they were at risk of relapse, they would typically attempt to reduce the demands by restricting their participation in activities that then led to reduced role performance²⁶ and withdrawal from occupational performance domains²⁷. However, in this study the first occurrence of impairment seemed to be the one that heralded intense anxiety for all participants. Subsequent relapses were associated with anxiety, but less than the first. This was clearly illustrated in the stories of those participants who experienced multiple relapses. The tendency was to move from a situation of shame and the need to hide the psychiatric impairment, with marked anxiety about the consequences that might be experienced, to greater openness and less anxiety during subsequent relapses.

Baumeister drew on two defining criteria of identity, namely 'continuity' (unity) and 'differentiation' to explain the cause of identity problems. He contended that a failure of identity components to provide continuity and differentiation would prevent the development of a 'stable' identity

²⁵ Described as "the failure of the *unifying* function of the identity component" (italics in original) Baumeister, R.F. (1986) *Identity: Cultural Change and the Struggle for Self*, Oxford University Press, Oxford..

²⁶ A broad awareness of a particular social identity and related obligations which together provide a framework for appreciating relevant situations and constructing appropriate behaviour. Examples are worker, student, parent, friend etc.

²⁷ Performance in work, leisure/play and personal life skills which are those required to maintain self and the life spaces in which functioning occurs.

(Baumeister, 1986:122). Two processes through which components are rendered ineffective in producing identity were highlighted; the first - 'destabilization' was described as "the failure of the *unifying* function of the identity component" (Baumeister, 1986:122 italics in original). Baumeister argued that the way one defined the self provided continuity only if it remained the same throughout life. If the component of identity changed, the unity of self over the lifetime would be lost. It is important to note that actual change is not required to weaken the ability of a component to define identity but that possible change or expected change could separate the present and future self from the past self. The second process - 'trivialisation', was defined to mean "the failure of the *differentiating* function of the identity component" (Baumeister, 1986:122 italics in original).

The functions of a 'stable' identity proposed by Baumeister appealed to me because it matched the beliefs held by many service providers involved in rehabilitation. These were, in summary (Baumeister, 1986):

- ◆ A clear sense of identity helps with making choices, in part because identity shapes the individual's own structure of *values and priorities*.
- ◆ A sense of identity is essential for the formation of interpersonal relationships: This aspect consists of social roles and personal reputation, also called 'social identity'. Interpersonal traits (for example friendliness) are combined with role-defining designations (for example being a mother or a teacher) to build a social identity. When identity is not well defined, or when it is in transition, relationships with others become difficult.
- ◆ A sense of identity impacts a person's sense of individual potentiality. This shapes the formation of personal goals and influences a person's belief about their ability to achieve a stated goal. This aspect has an influence on strength and resilience. The impact of setbacks or misfortune is reduced because of a goal-orientated approach that includes the fulfilment of particular potentialities.

The functions of a 'stable' identity as described by Baumeister were anticipated as constructive strategies that would facilitate participation in work. The statement of these functions was what initially led to Baumeister's ideas that seemed to be linked to participants' own positioning within the world of work. I operated on the assumption that the absence of a stable identity would interfere with functions such as those presented above. The limitations of such a simplistic set of assumptions however became clear when I tried to understand the concepts 'fulfilment' and 'potentiality' proposed by Baumeister as being closely linked and, importantly, as belonging to a 'stable' identity. Baumeister contended that an identity that contains a well-defined sense of potential "is more than just having an idea of something one could do. It is having a belief that personal fulfilment can be achieved by doing that something. The potentiality aspect encompasses identity's actual and possible goals" (Baumeister, 1986:20). These ideas were contradicted by the findings; in fact, the opposite seemed to be true.

Firstly, participants' stories suggested that flexibility in their accommodation of the impact of impairment on self-identity improved potentiality; flexibility rather than stability therefore seemed to promote continuation of valued roles. Disruption in the unity of identity occurred in the lives of all participants as a direct result of psychiatric impairment and also in anticipation of changes that might occur as a result of their illness. It became clear that participants who were able to absorb change and disruption by making accommodations and/or allowances for changes in identity, tended to continue their participation in valued roles, including the worker role. Simply put, participants who were able to 'embrace multiple identities' seemed better able to continue their participation in various life domains.

Conversely, an insistence on continuation of a stable identity resulted in some rigidity and also restriction of participation that interfered with recovery. A broadly held assumption (by service providers and participants themselves) that recuperation from relapse necessarily involved a return to a previously

held identity, before adapting back into life domains such as work, seemed to be a hindrance. The foundation for such an assumption might be the importance assigned to continuation of an identity that is deemed stable. The assumption was operationalised in expectations that participants would ideally regain a stable identity, one that had to be returned to after each relapse and one that was essential for continuity. Such an identity would form the springboard from which participation in domains such as work would be negotiated. Such a view placed the responsibility for re-gaining wellness on the shoulders of the person with psychiatric impairment, who is seen as somehow deficient if she is not able to accomplish this. An argument could therefore be made that the need for continuing identity might in fact have complicated recovery and interfered with decisions to participate in valued roles.

The point made here is illustrated by contrasting Robert's life story with that of Donovan's. Robert was working in a club house context, and chose not to enter into the transitional employment programme (TEP) that was offered. The TEP would have provided trial work opportunities for Robert to prepare for work in the open labour market with the ultimate goal of finding him employment. He worked once over a span of fourteen years as a messenger for a three week period. Robert, who had planned to become a lawyer, experienced a single breakdown weeks before completing his law studies. He held on to the same future plans, inflexibly refusing to revise them. Interestingly, Robert considered his education to be incomplete, thereby disregarding the three-year degree he had successfully obtained and that would have opened work opportunities if he wanted these. Donovan's story contrasted with Robert's. He had been working for a few weeks when he first experienced bipolar mood disorder. The initial years were very difficult; Donovan was incorrectly diagnosed and treated which resulted in numerous admissions. He had more jobs than he was able to remember during the initial stages of illness. Donovan also joined a Club House programme, and shortly after that he entered into the TEP. Whilst busy with his sixth TEP work

placement Donovan decided that he did not want to leave the company where he had been placed and he negotiated a long-term work contract for himself. This contract with the company was subsequently changed into a permanent position. Thus, Donovan seemed to benefit from the flexibility with which he was able to negotiate a changing situation. He emerged from disruptive and damaging early experiences of illness by adapting to changing circumstances whilst he looked for opportunities to shape such opportunities to his own advantage. Donovan had been the 'golden boy' of the family because he was 'bright' and also an entertainer (a member of a cultural band); this, he explained, made the early stages of illness difficult, like "falling off the pedestal". Donovan's life turned out to be different from the one he anticipated while growing up. His current job involved administrative work, something he never thought he would do. The TEP placements he had successfully completed were varied, most of these required that Donovan did manual labour; all were jobs that were far removed from the type of future he had anticipated for himself. Even in his current work Donovan had less prominence in the community than his family was used to having, but he compensated for this by becoming involved in public relations programmes at work. Donovan also took on an activist role for people with psychiatric disability; his experiences were portrayed in a number of local newspapers and he spoke at workshops or conferences where work and disability were discussed. He continued to attend a support group for those on TEP because he believed his own success would motivate others and because of the credibility he had within the group. Donovan reflected on the life he now had with some sorrow, explaining the hardships he had endured but also highlighting the good parts. He mentioned that he had become self-sufficient, more compassionate and that he was better able to prioritise and to recognise what was important.

Secondly, fulfilment did not emerge as an element that necessarily promoted potentiality. The stories of Donovan, Jessica, Sharon, Andrew, Nomisa and Thalitha all illustrated how significant periods of disruption, caused both by

psychiatric disability and other life circumstances, occurred at a young age and were experienced for prolonged periods of time. It is thus doubtful whether fulfilment in work (and other domains) would have been experienced as a regular occurrence, yet, the potentiality of these participants was clearly evident. Conversely, Robert, Christo and Joanne who all had previously experienced fulfilment (in keeping with the notion of a stable identity) before major disruption occurred were somehow more restricted in their attempts to participate in domains such as work. These participants seemed to restrict their own participation when opportunities available to them did not resemble their previously formulated experiences. For example, work opportunities in different categories and with lower social status were either not considered at all, or were considered but then discarded. Participants seemed to find the 'difference' between their currently available opportunities and prior situations too difficult to bridge, thereby restricting participation and as a result limiting their potentiality.

A further trend was that those participants, who were more at ease with the effect of psychiatric impairment, specifically those that could tolerate mild symptoms, seemed better able to maintain their role in the life-spaces in which they participated. By this I mean that they were more able to work and to socialise even while they might have been experiencing some symptoms; and at the same time also implementing strategies²⁸ to prevent the symptoms from becoming stronger. This stood in contrast with participants who attempted to 'take up where they left off' before symptoms were recognised. These participants seemed to maintain a focus on alleviation of symptomatology; taking the stance that they needed to be free of any symptoms before re-entering occupational performance domains.

²⁸ Examples were visiting a therapist to increase medication, changing routines to get more rest, cutting down on foodstuffs that are considered unhealthy or avoiding situations they perceived to be particularly stressful.

However, the same trend was not observed in participants who attempted to ignore the impact of psychiatric impairment on identity. Joanne is an example of somebody who had experienced relapse a number of times, but was doing what she could to frame her experiences differently. Despite an assessment that declared her medically unfit to work and which led to subsequent payment of disability benefits, Joanne continued to blame the termination of her career as a nurse on the matrons, who she felt were 'against her' because they favoured her ex-husband, also a nurse. She also explained her inappropriate behaviour in terms of the stress that accompanied the divorce she was going through at the time. Joanne attended clinic appointments as required, but did this because she feared her daughter would be removed from her if she did not. Being a nurse, one might have expected Joanne to recognise and admit that the medication she was using would be harmful to someone without psychiatric impairment; and that this would be evidence enough that she did have a bipolar mood disorder. Whilst Joanne remained unhappy with people believing she had a psychiatric impairment, she was supporting herself and her daughter on the disability benefits she received for her condition. She considered opportunities to work, but did not follow them through because she did not want to risk discontinuation of the disability benefits. Joanne was, in my understanding, someone who found it difficult to accept the changes to identity that resulted from having a psychiatric impairment. Instead, she regarded others who believed that she had a bipolar mood disorder with resentment.

In summary; Baumeister's ideas became problematic when the findings seemed to suggest that participants who attempted to return to 'the way things were' before they ever experienced psychiatric disability were seemingly more vulnerable. They were also finding it difficult to maintain their participation in life-spaces such as work. Participants who were more able to make allowances for the impact of psychiatric disability on their identity were seemingly more flexible in their approach to a life that was different from the one they were used to. Thus they were able to accommodate their fluctuating

health with less secondary impact (or damage) to their life-spaces than Baumeister's work implied. In other words, participants who were more comfortable with the notion of being different as a result of having a psychiatric impairment, seemed less anxious when they became aware of such differences in their every day lives. They would also readily admit to fluctuations they were experiencing that were the result of symptoms. Such admissions to themselves and others seemed to facilitate the use of strategies to alleviate or manage these fluctuations before damage was done to their life-spaces.

Baumeister's second criteria, differentiation, initially did not seem to be applicable to participants in the study. They did not show a strong need to be seen to be different. In fact it seemed an important focus of participants' lives to demonstrate their sameness to other people. Participants' narratives revealed their need to fit into what they perceived as 'normal' society. Participants displayed the tendency to create subcategories of people with psychiatric disability depicting various degrees of illness; examples of such categories were 'those who need long-term hospitalisation' or 'those who do not comply with medication' or 'those that are so self-involved that they live from support group to support group'. These subcategories were created with the aim to contrast themselves with people belonging to these categories thus emphasising participants' likeness to people who belonged to, and participated in, 'normal' society. In other words, participants had been 'buying in to' stereotypical constructs about psychiatric impairment. These same constructs were used to differentiate themselves from the stigmatised group of people with mental illness. Participants were at the same time differentiating from one group and emphasising likeness to general society; something that would prevent differentiation in ways that Baumeister considered to be an essential process for the development of a 'stable identity'.

Interrogation of participants' identity processes therefore problematised the notion of a 'stable' identity and seemed to contradict the functions proposed for such an identity.

8A.2. Punctualized Identity

Munro (Munro, 2004) proposed the idea of identity being *punctualized*: a "revealing of each specified identity within the here and now; and in response to the 'demand' of others" (Munro, 2004:294). An acceptance of Munro's idea would therefore imply that each person has the potential to reveal identities that would fit the demands of an 'other'. So, identities would be ready to reveal when 'called' forth by the demands of others in specific situations. For example, Siphon, who lived in the backyard of his family's home and kept to himself because he felt unwanted, was able to take a leadership role within the community group where he was working with other people with psychiatric disability.

Munro argued for the *positioning* effect, suggesting that a viewer should be 'locked in' to a particular standpoint to make a specific reading of identity. Again Siphon could be used as an example; his parents viewed him negatively as someone who had been difficult and oppositional. Their views were based on the decision he took to try to manage his impairment, by having himself circumcised²⁹. The community health worker in charge of the community group in which he was working held a very different view of Siphon and related to him as a potential leader of the group. A change in positioning can however also take place when a person comes to view another differently. An example would be Jessica's employer who initially did not know that Jessica lived with bipolar mood disorder. After Jessica told her, she seemed to

²⁹ Circumcision forms part of an initiation ceremony that all isiXhosa males are expected to undergo for them to be awarded the status of 'adulthood'.

understand Jessica's needs and was able to accommodate these. Jessica's employer's position might have been influenced by the fact that she herself lived with Parkinson's disease. Both these factors would have led to her being 'positioned' in a particular way.

Another component to be considered is the *timing* effect, which Munro explained to mean that "each 'call' demands a display of identity that annuls other 'calls' – precisely by overtaking these in the here and now" (Munro, 2004:294). He explained how the ideas contained in a *punctualized identity* offer a solution to the much contested notion of multiple identities that coexist, or the ideas of selves that freely inhabit social spaces. Instead the timing with which identities were revealed would mean that the one overtakes the other in the here and now (Munro, 2004). Four concepts come into play in Munro's model, these are;

- Revealing (or material extension): Identities are exposed in many different ways; and also by the effect created by materials in the form of 'belongings'.
- Setting-upon (or elicitation): Munro used Heidegger's phrase 'set-upon' to explain how other people have the power to elicit particular identities in complex ways, which would also reveal such power in the other.
- Challenging forth (Ordering Identities): This notion was based on Heidegger's 'challenging forth'; it affects relationships and identities. To understand this, the concept *enframing*, a translation of Heidegger's *Gestell*, should be considered. Munro explained that "within enframing, identity is punctualized: people stand 'on call', ready to produce an appropriate identity whenever it is challenged forth" (Munro, 2004:298).

These concepts helped to explain the complexity of considerations that affect the revealing of identities when it comes to psychiatric impairment and work. The meaning of 'challenging forth' (or ordering of identities) suggests that

orders for identities to be revealed can be more, or less, prominent for particular reasons. It is important to note that 'orders' which are absent can also be present. This aspect was clearly illustrated in the explanation of participants' preoccupation with the prevention of relapse. Even during those times when they were not experiencing relapse, participants were ever-aware of the possibility that relapse might occur sooner or later. This provided a plausible explanation for the restrictions in participation that participants regularly imposed on their own lives. The stigma associated with psychiatric impairment can similarly be positioned as an 'other' that will therefore call for the revealing of identity. It can be expected that this 'other' would lead to the revealing of identity that attempts to hide psychiatric impairment in order to avoid the anticipated negative consequences of stigma. Another, very different, 'other' might be a work opportunity, positioned to elicit an identity that contains the work skills and work habits that are valued in such a context. Participants' narratives revealed some tension between competing identities that had to be negotiated; tension originated when balance had to be maintained between, for example, worker vs. patient identity. 'Calls' for identity might therefore have been prioritised, or not, depending on the strength of one 'other' compared to another. These tensions are further complicated by the 'positioning' of the 'other' that is challenging forth the identity. Joanne, a qualified nurse, was offered employment as a carer for people that required home care. The idea of work appealed to her because she would earn a better income and she thought it would provide some meaning to her life. On the other hand, Joanne did not want to work because she would have to discontinue her disability insurance allowance³⁰. Joanne was not sure she would be able to maintain work and did not want to risk losing her income. In summary, 'revealing' (or material extension) relates to the way identities are exposed. For participants in the study 'revealing' was always complicated by the 'challenging forth' of identity. In other words, the

³⁰ Joanne was receiving disability benefits (a payment that disabled people qualify for) as well as payments from an insurance policy she took in her personal capacity.

identity that is produced at a given time will be influenced by an interpretation of the positioning of the 'other'.

Up to this point in the discussion an argument could be made that the experiences of people with psychiatric disability are not that different from people with other disabilities, or from other 'discredited'³¹ individuals. The difference for people with psychiatric disability was however explained when the impact of 'setting upon' was discussed. The last (of four) condition was 'setting upon' (or elicitation) in which Munro explained the condition through which an order is elicited or 'called forth'. Exploration of the 'setting upon' dimension explained very clearly how psychiatric disability is different from people with other disabilities. The nature of psychiatric impairment is such that it removes choice and control during revealing. The 'setting upon' condition is such that identities are 'called forth' entirely by the nature of the impairment; without the control or balance that comes from having a range of 'others' all positioned differently.

My interpretation of Munro's work was that psychiatric impairment takes over as the one 'other' that 'calls forth' identity. Firstly, it should be recognised that the psychiatric disability takes on the form of an 'other' with power to 'challenge forth' identities that are shaped predominantly or exclusively by the nature of the psychiatric disability (with variation according to impairment). Secondly, an identity revealed during stages of active illness will nonetheless have a lasting influence. Such a negative effect was particularly strong when participants came to recognise (after recovery from a relapse) that an identity that was revealed (during relapse), stood in contrast to current feelings, behaviour, judgements and choices. Negative experiences, positioned as an 'other', consequently lead to cautious or timid revealing of identity because of the shame and humiliation that had been experienced. Sadness and a sense

³¹ Stigmatised people who assumed that their difference was already known Goffman, E. (1963) *Stigma: Notes on the Management of Spoiled Identity.*, Prentice-Hall, Inc, New Jersey..

of loss was experienced when participants shared examples when the revealing of their identity, shaped by psychiatric impairment, led to embarrassment and damage that often touched them in deeply personal ways. For example, during Christo's first manic episode he resigned from work, planning to start his business; then sold a vehicle he owned, squandering the money on clothes, books, equipment and other "stuff" that he did not need. His family were motivated to step in when he ordered more than R12000 worth of sweets for a millennium party to which he was inviting total strangers that he found in the corridors of a shopping mall. The humiliation that came with the realisation of the damage he had caused himself was magnified by the fact that he prided himself as being someone who was a careful financial planner. Before his illness Christo had been in a better position (financially) than the rest of his family who from time to time relied on him when financial assistance was required. Now, he was not able to repay the debts he had incurred, and with the help of a lawyer had to explain the impact of bipolar disorder on his judgement at the time the purchases were made. The goods he purchased could not be returned because they had been stolen from his flat by the person (practically a stranger) that he had invited to live with him. Christo's look of bewilderment, as he shook his head at his own lack of judgement, bore testimony to the damaging effect his first manic episode continued to have on his identity construction. He could no longer trust himself in the way he could before, and had to admit that it would take years for him to rebuild his life.

An important component of Munro's ideas was the issue of time and its impact on identity; he explained the timing of identities to resolve the occurrence of multiple identities, with the one replacing the other at an exact time. Participants' stories revealed a similar pattern - but with a much longer timeframe between the replacement of one identity with another as influenced by the patterns of each particular psychiatric impairment (explained in 6.2.2. and 6.2.3.). They 'measured' stretches of time between episodes of relapse, even consciously positioning the shades of healthfulness

as 'others' that guided the revealing of identity. This pattern was, for example, observed when participants recognised symptoms or felt stressed, so that they would then make modifications to reduce life's demands. Participants' major goal was to prolong the time between relapses, but they seemed to anticipate that psychiatric impairment, in the form of relapse, would play a more or less dominant role in the 'calling forth' of identity (much as they tried to prevent this from happening). The consequence was that participants never looked too far into the future. It seemed that an expectation of the next relapse left participants with a tendency to make only tentative plans that were achievable in the here and now and with little attention to a future beyond that. When asked directly what their future plans were, participants would, without exception, refer to having a psychiatric impairment and the fact that they did not want to look too far into the future. With that said, most participants then shared their dreams for the future, but these were not usually translated into firm plans. Participants associated expected relapses with intense anxiety because of the fear that they might lead to;

- ◆ an altered sense of identity,
- ◆ changes in work status,
- ◆ damage to their relationships and
- ◆ reduced skills or abilities.

The complexity of forces that shaped participants' decisions to partake in, or refrain from work were better understood through interpretation of the mechanisms through which psychiatric impairment 'ordered' the revealing of identity. The 'setting upon' of psychiatric impairment, that took place in such a way as to remove the continuation of an authentic identity, meant that participants were left vulnerable and without much faith in their own ability to maintain work. A deeper exploration of the 'others' (including stigma) that are 'challenging forth' the revealing of contradicting identities would shed some light on the complex forces that influenced participants' decisions about work. It might clarify why some participants ended up avoiding work contexts, or

were experiencing unsustainably high anxiety levels whilst attempting to maintain work. In cases where it was known in the workplace that a participant lived with a psychiatric impairment, the stigma (positioned as an 'other') led to a pre-occupation with issues of competence. Participants would scrutinise the behaviour and comments of co-workers in order to decipher whether or not their contribution was being judged to be competent.

The narratives of participants who were not working showed that demands for the production of a work identity were arguably less often made than would have been the case if they did not live with a disability. This was because of a reduced expectation on the part of participants themselves, family (and friends) and also most other players in the world of work (employers and co-workers). The first reaction, that in some cases remained unchanged, was to believe that participants were no longer able to participate in work or even that such participation would be detrimental to their health. A broadly based assumption that stress at work would result in relapse, thus leading to a tendency to want to protect, often by limiting participation. The positioning of these 'others' led to elicitation (mostly not consciously) of an illness identity, or at least the type of identity that would lead to self protection. This was particularly true for those participants who had had one or more unsuccessful attempts to work. Some participants did not in fact have the readiness to maintain work participation when an opportunity to work arose (reasons for this will be explored later); this led to a reduction in the expectations of families or co-workers.

The complex influences on identity presented here were not necessarily consciously made. Whilst they were very aware of fluctuations in their own health, the accommodation of these on a day-to-day basis seemed to be done at a preconscious level. The flexibility with which participants were able to accommodate such shifts, revealing identities that had been challenged forth by changing sets of conditions, was found to be advantageous, as explained earlier in criticisms of Baumeister's work. In the absence of such flexibility

protective measures were used to prevent relapse. This included placing restrictions in the activities participants chose to engage in. To summarise, life with a psychiatric impairment required the complex revealing of identities by a range of 'others' that were in themselves complicated by the occurrence of psychiatric impairment. Social constructs of stigma have the power to elicit the revealing of identities that might be different from the revealing of an identity where stigma does not exist. When participants were not able to allow for the psychiatric impairment to have some impact in terms of shaping identity, they seemed less able to maintain participation. This is illustrated in the next section through the Model of Participation and Restriction.

Section B: The Model of Participation and Restriction

Introduction

During the final stage of analysis the Model of Participation and Restriction was conceptualised. It comprises clusters of influences that either hindered or fostered participation in occupation. The emphasis here is on work-occupations, but the model might be applied to other occupations.

The term 'model' has many different meanings; it has been described as a technique that assists the categorisation of ideas and structuring of approaches to thinking about complex problems (Creek and Feaver, 1993). It is often used with connotations that are similar to the concept 'theory'; something that has been avoided here. The Model of Participation and Restriction is meant to be read as an iconic model or 'pictorial representation' (Creek and Feaver, 1993) with its main function being explanatory.

Figure 8.1 The Model of Participation and Restriction



This model points towards participation in occupation, particularly work, or towards restriction from such participation. The categories shown behind a white arrow depict the broad influences that emerged from the data as those that impacted on the work-lives of participants. In other words, themes that emerged from the data were clustered to form the six domains of influence. The domains that were taken up in the model will now be briefly introduced (and explained later in more detail):

- ◆ Experiences of in-authentic identity: This domain captured the success with which participants succeeded in preserving an 'authentic identity'. Authentic identity is used to refer to the revealing of naturally occurring identities³²; 'in-authentic identity' refers to identities that are revealed after 'setting upon' of psychiatric impairment with resulting convergent identities being 'challenged forth'. A range of adjectives that were used to describe in-authentic identities that had been revealed during relapse indicated their lack of fit with authentic identities. These descriptions ranged from "unusual", "alien" and "strange" to "humiliating", "damaging" and "stupid". In-authentic identities usually stood in contrast to authentic identities, which often went against better judgement and did not honour deeply held values. It is important to understand that in-authentic identities were not only evident during stages of acute 'relapse'³³, when these were immediately obvious. Instead, the revealing of in-authentic identities was directly influenced by symptomatology and were therefore obvious or subtle depending on the participant's stage of illness or health.
- ◆ Experiences of otherness: This cluster comprised feelings of being different from other people. It also captured a sense of alienation experienced by participants when (1) they were hiding their impairment and thought that rejection or a change in attitude would occur if/when their psychiatric impairment became known, (2) stigma was experienced or anticipated, (3) misinformation shaped peoples' behaviour towards them and (4) during times when psychiatric impairment led to revealing of in-authentic identities. The experience

³² Natural is used here in the place of 'normal' which is problematic; (1) the term is often used in ways that discriminate, (2) relativism makes it meaningless and (3) participants often used the word 'normal' but then, usually, to refer to people without psychiatric impairment as a group.

³³ The term relapse is used to depict stages of the impairment during which the full range of symptoms required to make a diagnosis is observed; hospitalisation and/or other intervention strategies required.

of 'otherness' was exacerbated by a fear that permanent negative change could result from psychiatric impairment (for example, concentration problems led to fear of reduced intellectual capacity).

- ◆ Empowered by knowledge: The process of disclosure and explanations (regarding the impairment) that participants had, for themselves and for others, were captured in this domain. It explicates how knowledge was shown to improve the management of psychiatric impairment and to facilitate the continuation of valued roles. Accurate knowledge had the same positive influence on both participants and people who were in close contact with them. The sense of freedom, or constraint, that resulted from decisions about disclosure, was also included in this domain.
- ◆ Anticipation of stigma: This domain captured the extent to which experiences and anticipation of stigma interfered with role performance.
- ◆ Continuation of valued roles: Opportunities that allow for the continuation of valued roles was captured as a mechanism through which participants re-constructed their identities and restructured their lives.
- ◆ Experiences of support and fairness: This domain illustrates explain how (1) support and (2) experiences of 'being treated fairly' positively impacted on participants' ability to integrate and participate within their chosen life spaces.

The domains of influence are inter-related and, when colour is used in Figure 8.1 to depict their relative prominence, the person's tendency to either participate or restrict their involvement in chosen occupations is shown. Strong influence in a particular domain is shown in the model by filling the block with a darker shade of the same colour. The stronger the influence, the darker the shade that will be used; lighter shades depict weaker influences. The direction of the arrow 'shows up' when the influences impacting on participants' lives are depicted. The clarity and direction of the arrow, pointing

towards either participation or restriction, indicates the ease or difficulty with which participants are expected to participate in work.

Domains of influence are expected to shift in strength as they are shaped by life circumstances, processes of identity construction and by the inter-relatedness of influences. In keeping with Munro's ideas, the model might show a different inclination to participate in different contexts (for example a participant might engage in church activities but not in work). One reason for this is that people with psychiatric impairments might have had prior experience, and thus particular perceptions, about how safe it is for them to participate in each context. The attitude or 'positioning' of others in each context would similarly influence participation or restriction.

Munro put forward his idea of identity being *punctualized* as a solution to balance the privileging and counter-privileging of social identities and personal identities; depending on whether identity is considered the 'mirror of society' or a 'mirror of self' (Munro, 2004). For participants in this study both these domains were sources of influence that were either positive or negative and that affected participation in work.

The model was developed to allow for differentiation between the domains depicted above and below the line. All six components relate to identity construction. However, the upper three domains comprise influences that are situated in the inner awareness and that are used as a 'mirror of self'. The lower three domains comprise processes of identity construction that situates the person within their interactional experiences and that therefore functions as a 'mirror of society'.

8B.1. Explicating the domains of influences

Six domains of influence were incorporated within the Model of Participation and Restriction because of their tendency to guide participants towards restriction or participation in occupation; these will now be discussed. Theme(s) and categories that informed the development of these domains have been summarised in a diagram and included at the start of each section of the discussion (Figure 8.2. to Figure 8.7.).

8B.1.1. Experiences of in-authentic identity

Figure 8.2: Themes and categories that informed 'experiences of in-authentic identity' as a domain of influence.

LIVING WITH DIFFERENCE	ACHIEVING WELLNESS THROUGH WORK
6.1. Integrating competing identities	7.1. Establishing and maintaining a worker identity
6.1.1. Diminished by impairment	7.1.2. Starting again
6.1.2. Identity defined by others	7.1.3. Accommodating shifts
6.1.3. Balancing illness and worker identity	7.1.4. Decisions about disclosure
6.1.4. Balancing constructions of 'helper' and 'helped'	
6.1.5. Competing health views	
6.2. Strategies for healthy living	
6.2.1. Self imposed restrictions	
6.2.3. Maintaining equilibrium and holding uncertainty	
6.4. Identity rebuilding strategies	
6.5.1. Alienating consequences of impairment	

This domain is central to understanding how the disability experience is different for people with psychiatric impairment from other disabled people. Jessica and Suzaan's experiences have been used to illustrate how shifts in identity resulted in ambivalence about their chosen career and/or with job

satisfaction (7.1.3.). When in-authentic identity was 'challenged-forth' by the psychiatric impairment participants found themselves contemplating actions, decisions, plans or behaviours that differed from that which was natural to themselves. These would inevitably be reconsidered once identities being revealed were more authentic. The potentially very damaging impact of in-authentic identities on participants' lives was illustrated as something that could be deeply personal and have lasting consequences.

The disappointment of participants, when they recognised their damaging role in the disruption caused, was palpable. The knowledge that harm resulted from their own actions brought an added dimension of damage to self-identity that had to be re-constructed. In other words, participants had to undo the damage (for example loss of income and inability to find a new job) whilst also having to deal with the harmful impact on identity, in particular an inability to trust their own judgement. Little comfort was taken from the recognition that, during relapse, their control was diminished and they could not be held responsible. Participants internalised some of the blame because;

- ◆ they had failed to prevent the relapse,
- ◆ the lasting damage was theirs to undo,
- ◆ a negative impact on relationships could not always be undone and had a lasting effect,
- ◆ with each occurrence of relapse the prediction of future relapses became stronger – therefore a fear ensued that in-authentic identities were becoming who they were.

Psychiatric impairment is often portrayed as consisting of either wellness or ill health, in reality; shades of health and illness are experienced. In other words, participants were not always undergoing a stage of either 'perfect health' or 'complete relapse'. Periods during which symptoms had a subtle influence on important aspects of personality or on life choices occurred (usually shortly after discharge or during prodromal phases). During such episodes participants' judgement was usually not impaired but they

nonetheless experienced their life spaces differently. For some participants alterations in mood or volition would lead to a re-appraisal of their future plans; this made it difficult for them to maintain work. It should be noted that it was not the demands of the job that changed in this case, but participants' experiences of what the 'the best thing' was for them to do. This phenomenon was understood to be the result of relatedness of subcomponents comprising volition, for example interest and creativity. Even when participants were fully aware and had sound judgement, they were differently motivated to make particular decisions. Later, when symptoms had disappeared completely, participants would feel differently about the decisions taken, no longer believing these to be the 'best for them'.

In summary, this domain explains a confusing condition of psychiatric impairment; the appearance of an identity with particular elements, for example, mood, values, aspirations for the future, constructions of competence, ideas of own worth and perceptions that are different from those that usually characterise the identity of the person. Such an identity emerged from the psychiatric impairment and tended to vary in terms of the severity and the duration with which such elements were different from those that characterised the person. It is however important to note that whilst the intensity and duration of in-authentic identity was found to be hugely unsettling, it was not paramount in determining participation or restriction. The dynamic interplay of this domain with the other five domains presented in the Model of Participation and Restriction shaped such tendencies.

8B.1.2. Experience of otherness

Figure 8.3: Themes and categories that informed 'experience of otherness' as a domain of influence.

LIVING WITH DIFFERENCE	ACHIEVING WELLNESS THROUGH WORK
6.1. Integrating competing identities 6.1.1. Diminished by impairment 6.1.2. Identity defined by others 6.4. Identity rebuilding strategies 6.4.1. Finding positive outcomes 6.4.2. Reluctant reliance on others 6.5. Managing stigma, ignorance and prejudice 6.5.1. Alienating consequences of impairment 6.5.2. Environments characterised by stigma and prejudice 6.5.3. Balancing issues of stigma, ignorance and disclosure	

Otherness is used here to capture instances when participants were (1) feeling different from other people, (2) thought that they were not really known by other people or (3) they were treated by others as if they were different and (4) they were hiding their psychiatric impairment. A feeling of otherness was fuelled by misinformation, anticipation and experiences of stigma and the perceived threat that psychiatric impairment might lead to permanent negative change. Self-imposed restrictions, to prevent relapse, were reinforced by feelings of alienation or otherness. Participants would sometimes avoid doing something because they were genuinely worried about the pressure it would place on them. Situations were avoided because they worried that they would not 'belong'. The intensity ranged from feeling different in an awkward way, to fear of discrimination. Whilst tendencies to withdraw because of anticipated awkwardness were almost always located in

social contexts, the fear of discrimination was usually situated in work contexts. It was as if participants had developed a hierarchy in which their anticipation of otherness increased as the contexts (and people) moved from known to unknown and from social to work.

The experience of otherness was obviously influenced by occurrences of in-authentic identity because it affected the perceived 'goodness of fit' between identities that were 'challenged forth' and those that were being 'revealed'. When in-authentic identities had been 'revealed' the nature of such identities would result in the re-'positioning' of co-workers. Chriselda's experiences serve as an illustration. Having had her first episode of mania whilst at work, she understood that her co-workers would now have a different view of her; one that contrasted with the picture she believed was important to portray if she was to be taken seriously as a fashion designer. She experienced different dimensions of otherness; (1) whilst in-authentic identity was being revealed (less intense before and after the period of psychosis) – this had to do with a lack of 'fit' between authentic identity and in-authentic identity and (2) returning to a work context in which co-workers experienced her differently.

Interestingly, hiding psychiatric impairment seemed to result in a sense of enduring otherness and also of distance. Participants seemed to operate on the assumption that once their impairment became known the 'positioning' of others would change. This expectation of rejection nullified experiences of closeness and acceptance because these were positioned as 'not being real'; in fact such positive experiences reinforced a sense of otherness and distance because they illuminated the loss of 'what it could have been like' had it been real. Jessica's fragmented work history before she first made a decision to disclose her illness had a lot to do with the otherness she was experiencing. Jessica herself identified that the problem was she "looked the part". She could get away with not revealing when and how she was being affected by Bipolar Mood Disorder for periods of time. A constant experience of otherness

and the fact that workplace accommodations could not be made meant that sustaining work for longer than three months was not comfortably achieved. This changed completely when Jessica disclosed to a new employer. She was able to ask for small accommodations (for example that the background music being played be changed) and felt free to speak about the symptoms she was experiencing from time to time. Jessica explained how her new openness led to her feeling less pressure to keep up the façade she previously believed was necessary. Her disclosure and her co-workers' acceptance resulted in a feeling of belonging; a feeling that contrasted with earlier feelings of otherness and distance.

In summary, it was soon clear that some participants were avoiding work contexts or work opportunities in anticipation of stigma or relapse. Participants usually framed their reasoning for such avoidance in terms of needing to prevent relapse. However, when participants were reflecting on work experiences they had had, the otherness they experienced was palpable and might have been the stronger influence.

8B.1.3 Empowered by knowledge

Figure 8.4: Themes and categories that informed 'empowered by knowledge' as a domain of influence.

<p>LIVING WITH DIFFERENCE</p> <p>6.5. Managing stigma, ignorance and prejudice</p> <p>6.5.1. Alienating consequences of impairment</p> <p>6.5.2. Environments characterised by stigma and prejudice</p> <p>6.5.3. Balancing issues of stigma, ignorance and disclosure</p>	<p>ACHIEVING WELLNESS THROUGH WORK</p> <p>7.1. Establishing and maintaining a worker identity</p> <p>7.1.3. Accommodating shifts</p> <p>7.1.4. Decisions about disclosure</p> <p>7.3. Work as a means of managing identity</p> <p>7.3.1. Validation of wellness and worth</p> <p>7.3.2. Integration through interaction and contribution</p>
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Improving knowledge about the experience and the nature of psychiatric impairment was something that greatly assisted participants themselves, as well as co-workers and family members. Disclosure was an obvious requirement before the knowledge of family members or co-workers could be improved. It empowered those people who worked alongside psychiatrically disabled people to make informed decisions about their behaviour. However, two particular categories influenced this domain; (1) understanding impairment (embedded in intellectual insight) and (2) knowing how to disclose impairment (a process that relied on acceptance).

Understanding impairment

Participants consistently found it difficult to explain their illness to other people; some found it difficult to understand their own illness. This led to feelings of alienation and otherness that in turn brought anxiety. Such anxiety seemed to reduce participants' ability to be flexible about the impact of their impairment, therefore causing them to guard vigilantly against what would be considered causes for relapse. Once participants understood their illness experience and were able to identify the true danger signs, they no longer needed to protect themselves to the same extent. It was also then that participants would risk telling others that they were in fact living with a psychiatric impairment. In these cases, participants were able to be flexible about the impact of their impairment and secondary damage³⁴ was limited. Restriction occurred when the impact of impairment caused levels of 'discomfort' that made it easier for participants not to be a part of the work context. They could either refrain from attempting to participate in work, or were easily unsettled, to such an extent that work was not maintained. A heightened sensitivity, explained by feelings of otherness and reduced

³⁴ Damage that resulted from (1) too much restriction (opportunities are missed) or (2) unwise actions taken during relapse (because symptoms are not recognised).

confidence in work ability, meant that participants felt that they did not belong. The reasons for withdrawal from work or social context very often related to a belief that they were incompetent or not wanted. For both participants, and their co-workers, the psychiatric impairment might have become a 'scapegoat' for difficulties that occurred at work. Good knowledge of the signs and symptoms as well as the possible causes of relapse seemed to assist a great deal, placing people with psychiatric disability in a position of managing their impairment better. The type of knowledge required here was about gaining intellectual insight; participants themselves, families or co-workers acquired knowledge through information shared or via experience. It is therefore the type of knowledge that would be included in an education programme. The second category of knowledge required was situated in the emotional experience of people and shaped attitudes and decisions about disclosure. This cannot be taught easily, relies on experience and can be constrained by processes of acceptance (for people with psychiatric impairment and others).

Knowledge reduces alienation

When participants worked, and did not disclose their impairment, they experienced generalised anxiety about their competence and fit in the workplace. Even when they were doing well at work, such participants were not able to trust the situation; they seemed to expect that they would be 'caught out' and that once this happened they would be treated differently. They could be 'caught out' by somebody finding out that they had a disability or by the impairment itself when relapse occurred. Participants were therefore always alert at work, fearing that they might experience symptoms that would show, maybe without they themselves noticing. The experience of participants who had disclosed their disability was very different. They were more readily able to trust positive feedback (obtained from others and from their own experience) as true and deserved. It seemed that disclosure reduced anxiety by authenticating the person with psychiatric impairment as a

legitimate part of the work context. Obstacles seemed easier to identify and were discussed openly. Chriselda’s comment that “the worst has happened”, captured the key difference between participants who disclosed and those who did not disclose. For those who did not disclose, the worst that could happen was that symptoms would show; something that realistically could occur at any time and over which they had little control. The vulnerability that resulted when participants chose not to disclose was therefore significantly higher.

The interrelatedness of this domain with the previous two should be clear – each influenced the other to impact participants’ behaviour. The same is true for the next domain.

8B.1.4. Anticipation and experiences of stigma

Figure 8.5: Themes and categories that informed ‘anticipation and experiences of stigma’ as a domain of influence.

<p>LIVING WITH DIFFERENCE</p> <p>6.1. Integrating competing identities</p> <p>6.1.1. Diminished by impairment</p> <p>6.1.2. Identity defined by others</p> <p>6.5. Managing stigma, ignorance and prejudice</p> <p>6.5.1. Alienating consequences of impairment</p> <p>6.5.2. Environments characterised by stigma and prejudice</p> <p>6.5.3. Balancing issues of stigma, ignorance and disclosure</p>	<p>ACHIEVING WELLNESS THROUGH WORK</p> <p>7.1. Establishing and maintaining a worker identity</p> <p>7.1.1. Opportunity to develop a worker identity</p> <p>7.1.2. Starting again</p> <p>7.1.3. Accommodating shifts</p> <p>7.1.4. Decisions about disclosure</p> <p>7.3. Work as a means of managing identity</p> <p>7.3.1. Validation of wellness and worth</p> <p>7.3.2. Integration through interaction and contribution</p> <p>7.5. Obstacles encountered</p> <p>7.5.1. Unfair dismissal</p> <p>7.5.2. Promotion withheld</p>
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The stigma associated with psychiatric impairment is pervasive; a key ingredient in the construction of disabling environments and life with a psychiatric disability. It is interesting to note that when participants were known on a personal level before they first experienced psychiatric impairment, they were accommodated within the workplace, with employers and co-workers naturally changing rules or work demands in order for participants to continue working. However, these same participants doubted if they would have been employed had the employer known of the psychiatric impairment. An explanation for this discrepancy might be that stigma was in fact a pertinent influence in the work culture, even if participants perceived themselves as having been spared such treatment. In other words, psychiatric impairment was obviously still not accepted (illustrated in jokes or comments made by co-workers) but because participants were known they were not placed in this category. Rather than realising that issues of mental illness were misunderstood, the tendency was to maintain faulty concepts of 'madness' whilst accepting the person they had got to know well as different. The surprising, and somewhat distressing finding was that participants themselves stigmatised psychiatric disability. It was not ever directly expressed, but was seen in the following ways:

- Participants had developed 'categories' of people with psychiatric impairment. Within these categories those who were closer to 'normal' were somehow superior. Other people with psychiatric disability became the focus of pity.
- Participants were surprised by examples of people with psychiatric impairment who were doing well at work and also by fair treatment. It demonstrated that participants subscribed to social constructions in which people with psychiatric impairment were being cast as unable to maintain work.
- A deep-seated experience of 'otherness' that participants experienced in all their life spaces. This is something that was expressed directly, and also shaped participants' reasoning and decision-making. This otherness emerged from feeling that other people did not understand

psychiatric impairment. It also appeared to relate to the fact that participants themselves were not able to explain or predict exactly what was happening to them.

- Participants spoke about their own stigmatisation and negative attitudes before they first experienced the impairment. These had a big impact on their anticipation of how they felt that they were viewed by other people in society.

The anticipation of stigma was a strong influence that led to self-protective mechanisms. Some participants experienced discrimination; others changed their behaviour in anticipation of discrimination. Anticipated discrimination seemed to have a bigger impact on participants' behaviour and the decisions they made than actual experiences of discrimination had.

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8B.1.5. Continuation of valued roles

Figure 8.6: Themes and categories that informed 'continuation of valued roles' as a domain of influence.

<p>LIVING WITH DIFFERENCE</p> <p>6.2. Strategies for healthy living</p> <p>6.2.1. Self imposed restrictions</p> <p>6.2.3. Maintaining equilibrium and holding uncertainty</p> <p>6.4. Identity rebuilding strategies</p> <p>6.4.1. Finding positive outcomes</p> <p>6.4.2. Reluctant reliance on others</p> <p>6.5. Managing stigma, ignorance and prejudice</p> <p>6.5.3. Balancing issues of stigma, ignorance and disclosure</p>	<p>ACHIEVING WELLNESS THROUGH WORK</p> <p>7.1. Establishing and maintaining a worker identity</p> <p>7.1.1. Opportunity to develop a worker identity</p> <p>7.1.2. Starting again</p> <p>7.1.3. Accommodating shifts</p> <p>7.1.4. Decisions about disclosure</p> <p>7.2. Work well matched</p> <p>7.2.1. Accommodations at work</p> <p>7.2.2. Supported employment</p> <p>7.2.3. The Transitional Employment Programme</p> <p>7.2.4. Support at work</p> <p>7.3. Work as a means of managing identity</p> <p>7.3.1. Validation of wellness and worth</p> <p>7.3.2. Integration through interaction and contribution</p> <p>7.4. Motivation for, and obstacles to, work</p> <p>7.4.1. To earn money</p> <p>7.4.2. Responsibility for family</p> <p>7.5. Obstacles encountered</p> <p>7.5.1. Unfair dismissal</p> <p>7.5.2. Promotion withheld</p>
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The continuation of valued roles, I would argue, became a mechanism around which participants re-constructed identities. When the nature of occupation demanded it the required identities were revealed. A range of different roles were mentioned by participants, work being an important one of these. Other such roles were that of family member and religious participant. The performance of valued roles, when considered together with Munro's ideas of a *punctualized identity*, would mean that participants' identities were revealed

in response to demands by 'others'. Each of the roles performed could be positioned as such an 'other' and would therefore elicit identities that would lead to successful performance of such a role. The question at hand is therefore whether an ability to reveal such identities allows for continuation of roles, or whether the opposite is true. By this I mean to suggest that the demands inherent in role performance might lead to an improved ability to continue valued roles. Suzaan, for example, identified being a single parent and thus having to care for her daughters as the main reason to continue working despite years of repeated relapse. The mechanism through which she cared for her daughters was to ensure that she maintained her work participation.

8B.1.6. Understandings of fairness and support

Figure 8.7: Themes and categories that informed 'understandings of fairness and support' as a domain of influence.

<p>LIVING WITH DIFFERENCE</p> <p>6.1. Integrating competing identities</p> <p>6.1.4. Balancing constructions of 'helper' and 'helped'</p> <p>6.4. Identity rebuilding strategies</p> <p>6.4.1. Finding positive outcomes</p> <p>6.4.2. Reluctant reliance on others</p>	<p>ACHIEVING WELLNESS THROUGH WORK</p> <p>7.1. Establishing and maintaining a worker identity</p> <p>7.1.1. Opportunity to develop a worker identity</p> <p>7.1.2. Starting again</p> <p>7.1.3. Accommodating shifts</p> <p>7.1.4. Decisions about disclosure</p> <p>7.2. Work well matched</p> <p>7.2.1. Accommodations at work</p> <p>7.2.2. Supported employment</p> <p>7.2.3. The Transitional Employment Programme</p> <p>7.2.4. Support at work</p> <p>7.3. Work as a means of managing identity</p> <p>7.3.1. Validation of wellness and worth</p> <p>7.3.2. Integration through interaction and contribution</p>
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Support was an important facilitatory influence that shaped the lives of a number of participants in significant ways. Even when participants were seemingly unable to find or maintain work on their own, they were able to do so when the correct support was provided. The nature of support that was found helpful varied. Practical support could be given by anyone, including family and friends. Employers and co-workers provided general support at work and assisted in making accommodations. There was however a dimension of support that required a relatively sophisticated knowledge about psychiatric impairment (its impact on people and their relationships) and about matching ability with work requirements. Recognition of the particular shifts in identity brought about by psychiatric impairment was required when the support offered was aimed at maintaining work participation.

Participants hailed support as an important positive influence during processes of finding and maintaining work. Yet they revealed their ambivalence about needing support when they were easily irritated by being offered it. Participants often singled out incidents when support was offered in a way that was perceived to be patronising. Their conflicting feelings also became clear during interviews when participants explained how grateful they were for support, and then shortly after, their words expressed irritation about the same support. At any stage attempts to dictate, or give unsolicited advice were met with resistance.

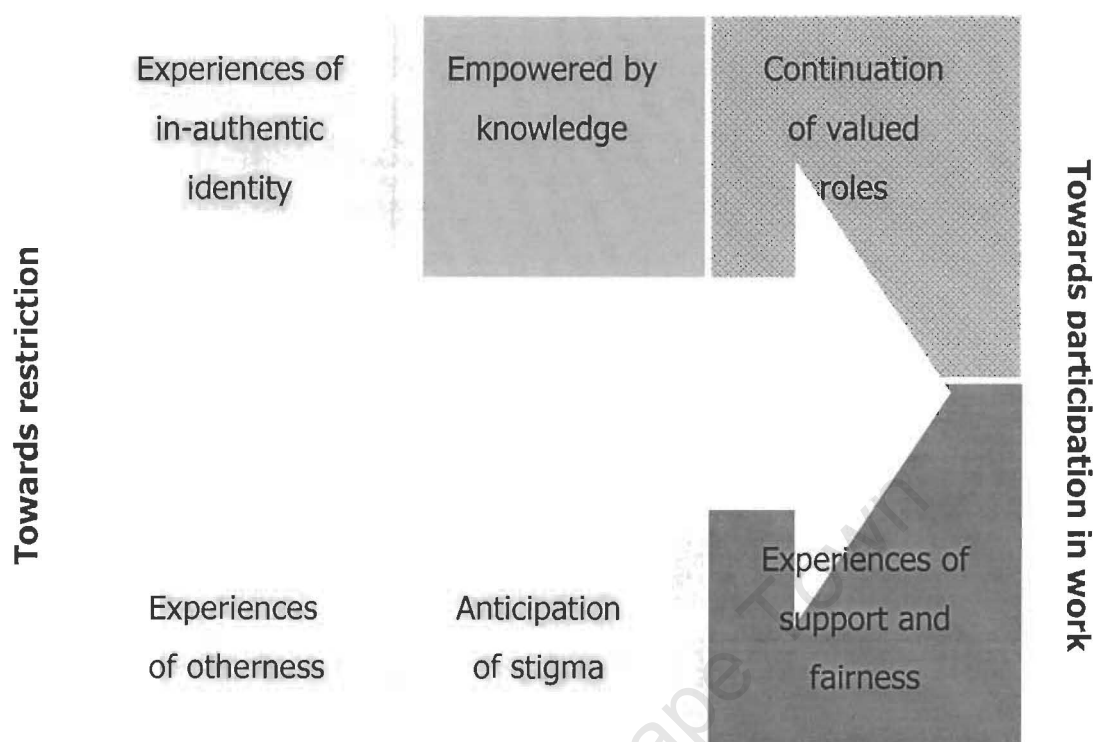
Participants were not always able to express their negative feelings associated with needing support. This might have something to do with the fact that participants remembered times when they had to rely on the 'better judgement' of other people during a relapse – despite being convinced at the time that they did not need to do so. These memories interfered with relationships in that participants were not always able to assert their own views because (1) they knew that they might need support from the person again in future, (2) the other person might have knowledge of previously damaging consequences of impaired judgement (and therefore become over-

protective), (3) participants were reminded of experiences during relapse which they associated with their need for support.

8B.2. Applying the model

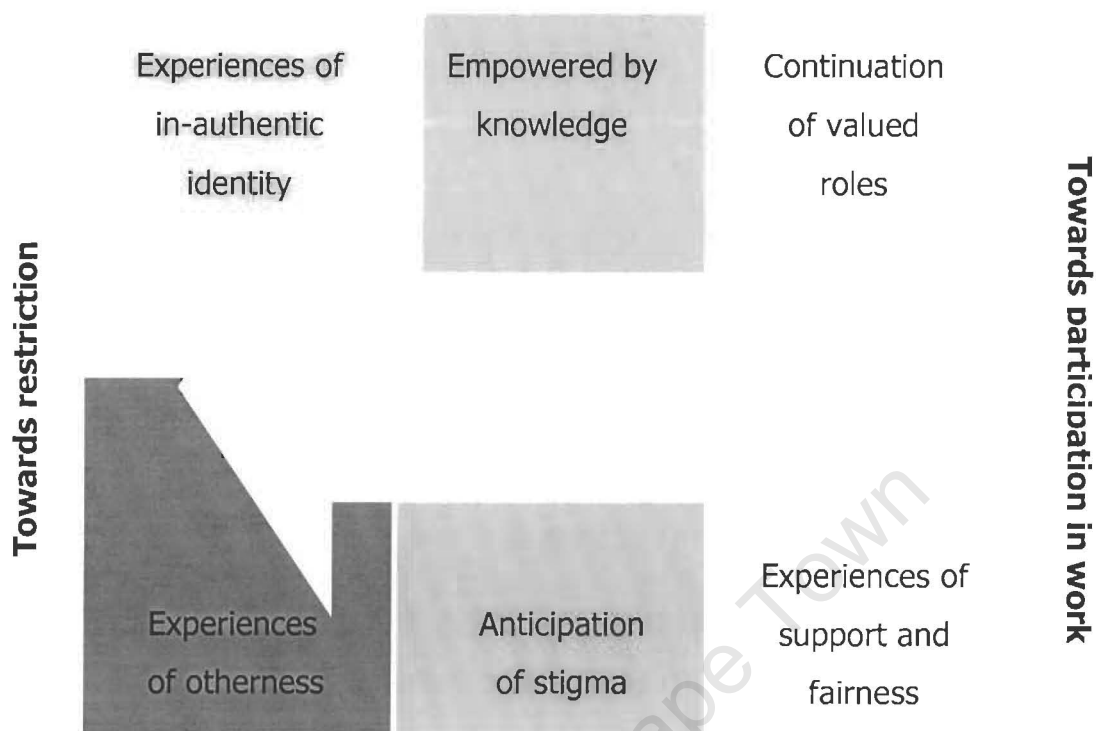
The key to understanding the influence of each domain contained in the Model of Participation and Restriction on 'participation' or 'restriction' is to understand that the domains all impact on one another. It is therefore the interrelatedness of domains that will reveal a person's tendency to attempt participation in occupation or to restrict such involvement. The differences between Robert and Donovan, discussed earlier, will be used to illustrate the use of the model. When a domain was believed to be strongly evident in a participant's life a darker colour was used to fill that domain. Conversely, domains with no correlation to participants' experiences were not emphasised with colour. Shades of the same colour are therefore used to depict stronger or weaker influences.

Figure 8.8 Influences that impacted on Donovan's ability to work



The Model of Participation and Restriction was completed to depict the influences that were understood to impact on Donovan in his work context. It is clear from the model that the stronger influences were the ones that motivated Donovan to participate in work. The opposite picture would have been presented if the model had been constructed during the early stages of Donovan's impairment. The influences that have an impact on Robert's participation are depicted below. In Robert's case the model would not have changed much from earlier to later stages.

Figure 8.9 Influences that impact on Robert's ability to work



It is however important to note that this model was completed to depict a particular work context – in which Robert participated for only three weeks. If the context had been the Club House which Robert attended daily, it would have looked very different.

Section C Implications of the model

8C.1. Occupational injustice and the implications for occupational therapy

This study was located in South African occupational therapy, which has seen considerable change and adjustment in the past ten years. The hallmark of

occupational therapy, throughout history, has been its focus on 'what people do' and on holism. These important characteristics of the profession have been strongly evident in the rhetoric, but mostly absent in practice. Whilst there are examples of very good practice in occupational therapy, the critique offered here refers to earlier practice examples in the field of psychiatry in South Africa. Practice was directed primarily at vocational assessment and vocational rehabilitation services with very little carry-over to natural work contexts.

The situation with work and people with psychiatric disability remains as an example of occupational injustice. This assertion is supported by Whiteford's explanation that occupational injustice will result from the condition of prolonged exclusion from occupations of meaning and/or necessity when such exclusion is due to external forces over which the individual, family or community does not have control (Whiteford, 2004).

When occupational therapists confront the issue of occupational injustice, they have to re-think current practice. Occupational therapy should promote participation in occupation across all systems levels (individual, institutional, societal). Current practice settings with work as a specific focus are too focussed on the alleviation of symptoms, without sufficient attention being given to promoting participation in work as a final outcome. Health services for people with psychiatric disability, within which occupational therapists work, are mostly limited to the treatment of acute illness. There is little extension of these services into natural life spaces within which participants live and work after discharge. When occupational therapists are involved in promoting work participation, the scope of their involvement is often limited to doing a work assessment without follow through to actual work settings. When work assessment is done, participants are invariably left on their own to find work within a macro environment that is characterised by high levels of unemployment. Other options for work are also not discussed with the person.

These limitations in the services available do not only emerge directly from the occupational therapy profession per se. Instead, they are due to the way health services in South Africa have developed. The mistake that the profession made was to remain closely aligned with practitioners and services that were purely utilising the medical model in their approaches. For example, psychiatric services developed around the need to reduce and maintain symptoms. Occupational therapists did not position themselves in contexts in which they were best able to promote the occupational behaviour needs of their clients. With government being the only real employer, occupational therapists work predominantly in hospital contexts where the dominant focus is curative. Little attention is given to promoting healthy living within the natural life spaces of people with psychiatric disability.

Conclusion

The processes involved to *maintain participation*, despite disruption brought about by psychiatric impairment, is a process that is often over-simplified when the many influences that impact on it are not understood. The processes that shape participation in work cannot be simplified to particular skills, attributes or abilities. Instead, participation in occupation is shaped through the interaction of the influences depicted and the involvement of people with psychiatric impairment, their co-workers and families. The Model of Participation and Restriction, developed out of this study, offers a mechanism through which sense can be made of the complexities that impact on obtaining and maintaining work.

Chapter 9: CONCLUSIONS and RECOMMENDATIONS

Introduction

In this chapter limitations of the study will be explored before the conclusions and recommendations are presented. Initial attempts to separate conclusions and recommendations led to repetition and fragmentation; these are therefore presented together. A differentiation will however be made to separate the domains to which recommendations are directed, namely service, legislation and research.

The conclusions and recommendations presented in this chapter were formulated during the steps taken as part of the research process:

- ◆ Most were realised during the three levels of analysis and interpretation that culminated in the development of the Model of Participation and Restriction.
- ◆ Development of thinking took place during reflections that were sparked by key questions. These questions arose after discussions with colleagues when provisional findings were shared.
- ◆ The literature reviewed contributed to the development of ideas in that it confirmed some views that were held at the onset, contradicted others and led to the development the understandings shared here.

9.1. Limitations of the study

9.1.1. *Limitations of Life Story research*

Plummer highlighted three main problems with the use of life stories. The first is that "there is a copying and commodification effect" (Plummer, 2001:100). He explained that stories can be repeated and rehearsed, or even exchanged

or sold, resulting in a loss of authenticity as such stories could become a cliché. His second concern is closely linked, and highlights that life story telling could become a “technology of the self”: one through which power is dispersed and lives are constituted and regulated” (Plummer, 2001:100). With the many new ways in which life stories are used, in forms such as film, electronic mail, video, television, various types of therapy etc., could mean that they come with a reduced impact and worth. The third problem introduced by Plummer is “the fear of an excessive individualization and personalization” (Plummer, 2001:100). Plummer’s concerns were considered but found not to apply in this study because most participants were telling their stories for the first time. Donovan was the exception. He had had a newspaper interview in which he shared his life story before the study. However, it was the first time he shared his story from a perspective or work performance. Participants were furthermore aware of the confidentiality agreement, and understood that their stories would not be linked to their identities when findings were disseminated.

9.1.2. People with psychiatric impairments and use of (auto)biography

Stone considered the implications, possibilities and dangers of addressing the experience of ‘madness’ within autobiographical narrative (Stone, 2004). His specific focus was to understand how madness can be narrated, or spoken. Stone contended that “madness is, after all defined, one might say constructed, but its very difference from reason, and also, to some extent at least, by its variance from the readable forms of narrative” (Stone, 2004:18). Stone explained that whether the person was describing her experience from *within* madness, or from a position situated outside it, there would appear to be a disjunction between the content to be narrated and the possibilities of narrative form. Similar questions were asked by colleagues, for example the ethics committee that approved this study, during the initial stages of the

research. These concerns did however not apply; principally because participants did not focus their life stories or self stories on their experience of 'madness' but on the experiences of participation in work. Care was taken to spread the interviews over a period of twelve weeks. Fluctuations in mental state would therefore have been recognised. My experience was that participants themselves were aware of fluctuations in their wellness and that they openly discussed the impact of this.

9.1.3. Limitations brought by the scope of the study

The use of interpretive biography in this study yielded a perspective of influences that were rooted in the experiences of participants. Thus, no claim can be made to have developed a comprehensive understanding of all influences that would impact on the work-lives of people with psychiatric disabilities.

9.1.4. Limitations brought by the design of the study

Sampling strategy

The strategy used for sampling was informed by a need to respect the right of participants to refuse participation in the study. Care was taken to reduce power dynamics that might have led to potential participants agreeing to enter into the study because they were not able to refuse. Potential participants were therefore approached by service providers who were known to them. Only after agreeing that they were interested to participate did service providers provide contact details to the researcher. This strategy led to the following limitations:

- ◆ Disclosure issues: Only two participants in the study had not disclosed their disability status by the time that the first interviews were conducted. As previously discussed, participants in the study all experienced disclosure as having had a number of positive spin-offs. This might be due to the fact that participants who agreed to participate in the study were the ones who had had positive experiences following instances of disclosure. An argument could be made that people who might have experienced negative consequences as a result of disclosure would not have agreed to participate in the study. All potential participants were given an indication that participation in the study would involve up to three interviews during which they would be asked to 'tell their story'.
- ◆ Balancing interpretations of psychiatric impairment: Variation in the health beliefs and worldviews within which participants would have understood the occurrence and best management of psychiatric impairment has been discussed. A major portion of South African society might interpret the occurrence of psychiatric impairments in ways that are different from western interpretations. Participants in this study aligned themselves more closely with Western interpretations and solutions for their impairment; only one participant was strongly influenced by traditional interpretations. No claim is therefore made to have understood the influences that impact on the lives of people with psychiatric impairment who strongly align themselves with traditional interpretations.
- ◆ Incorporation of definitions and views of mental health: The concepts of mental illness and mental ill-health are by design very broad. They include people who are not users of mental health services but who experience difficulty coping in the modern workplace and who consult general practitioners for mental ill health. The present study purposefully did not include this category of worker. This is in keeping

with research done and literature published that focuses mostly on people with serious mental health concerns.

9.2. Recommendations for Service

The literature reviewed confirmed that predictions about ability to work, based on diagnosis or symptoms, could very seldom be made. In fact, the findings of the present study suggest that such predictions should not be made because;

- ◆ participants' life-stories revealed how some participants whose lives had been severely disrupted by repeated experiences of relapse were sometimes better able to maintain work than those who had experienced fewer barriers,
- ◆ opportunities for participation in valued roles fostered participation,
- ◆ processes of identity construction and recovery were deeply personal and complex – generalisations could therefore not be made,
- ◆ strong influences that shaped participation were elusive in nature and was difficult to measure.

Strong domains of influence that were found to determine the tendency of participants to want to participate, or to limit such involvement, were included in the Model of Participation and Restriction. The character of these domains posed inherent limitations as well as inherent opportunities. The limitations are that (1) they are very different from variables that would ordinarily be considered important (and therefore receive attention in vocational rehabilitation programmes) and (2) they are not measurable or observable (therefore complicating research). The opportunities are tied with their phenomenological nature. In other words, the domains were about lived experience and about participants' identity construction processes – something that could be explored and changed through processes that would improve insight. Simply put, people with psychiatric disability could (1) be

made aware of the domains of influence, (2) reflect on the impact these influences might have had in their own lives, (3) be assisted to resolve issues that pressed for resolution and (4) be given the opportunity to participate in valued occupations.

The domains of influence that were found to shape 'participation' or 'restriction' are those that would not usually receive attention in traditional vocational rehabilitation services and hence are believed to have been neglected. Whilst these influences are complex and often neglected, their nature will allow positive change through strategies that will explicate their impact. In other words, participants could be assisted to counteract the negative impact originating from the domains of influence by following the four steps mentioned above.

9.2.1. Services should be broadened and naturalised

Participation in regular work alongside non-disabled people with similar status was, for most participants, their ultimate goal. Such participation was not promoted by a traditional medical model focus on alleviation of symptoms. The alleviation of symptoms was however important because of in-authentic identity being stronger whilst psychiatric impairment was not being managed well.

A first criticism of vocational rehabilitation programmes in the South African context is that these are usually situated in hospitals or other institutional contexts. Follow through into natural work contexts has not been offered as a part of these programmes. The implication is that people with psychiatric impairment who are suited to work in competitive employment have been left to their own devices post discharge. A second criticism is that people with disability are expected to fit into a world created to meet the needs, and match the abilities, of non-disabled people. Emphasis should however also be

placed on changing the environment; to remove barriers that prevent equal participation of disabled people. This would be in line with the Social Model of Disability that considers the burden of disability to result from environmental barriers rather than from the impairment or health condition. Such a stance would furthermore be closer aligned with South African labour legislation and more in keeping with the promotion of occupational justice. Reasonable accommodation should therefore be made in order to equalise opportunities for maintained work.

Natural work contexts are important

A key ingredient that led to maintained involvement in work seemed to be a sense of 'belonging' or, in other words, for experiences of otherness to be resolved. Ongoing successful participation in work seemed to be a powerful ingredient that fostered success. The power of this domain was understood to be linked to the resolution of otherness. Maintained participation in valued occupation reduced experiences of otherness and vice versa. It also indirectly assisted with the preservation of authentic identity. When work was continued, despite moderate symptoms, the alienating consequence of inauthentic identity was reduced. This improved the flexibility with which identity shifts could be accommodated without secondary damage being experienced. The complex interplay of domains contained in the Model of Participation and Restriction suggests that vocational rehabilitation should be placed within natural work contexts. Without the natural context, experiences of otherness cannot be resolved and the disabled person might not develop a reliable worker identity. A reliable worker identity appeared to develop when a real contribution was made in the work place whilst being accepted by co-workers who knew about the worker's psychiatric impairment. The acceptance of others, who knew about the psychiatric impairment, had a remarkably positive impact on resolving experiences of otherness.

Opportunities for participation should be safeguarded

The devastating consequences for participants who made decisions they later regretted is something that should receive more attention. Participants invested time, energy and focus on the prevention of relapse, living with this as a main goal every day of their lives. Every opportunity, work or social, was scrutinised for the amount of stress or pressure it would place on them. Participants let go of opportunities in order to prevent the occurrence of relapse. It however became clear that, when participants knew that work was safeguarded from interference of psychiatric impairment, as was the case with Galiel, they were better able to continue their participation. Knowledge that the damage brought by impairment could be contained seemed to reduce the threat posed by in-authentic identity and therefore allowed greater flexibility. This, in turn, facilitated participation.

Finding a broader base to fund service

Cost is an obvious and immediate consideration in South Africa. Psychiatric service delivery does not (yet) meet the envisaged standards and coverage. Vocational programmes as such do not receive government funding; instead, subsidy has been allocated to sheltered and protective workshops. Vocational rehabilitation programmes have consequently been shaped to cater predominantly for the needs of people who are eligible to fit into sheltered and protective workshops. People with psychiatric impairment seldom fit into this group, which usually comprise mostly people with intellectual impairment. A view can be taken that employment of people with psychiatric disabilities fall into the domain of the Department of Labour, as much as it belongs in services provided by the Department of Health. Such a broadening of responsibility should unlock resources that have thus far been unavailable. The involvement of Sector Education and Training Authorities (SETAs) should advance the development of programmes that foster participation of people with disabilities in the world of work. The legislative framework to make this

possible is already in place, it is now up to service providers, particularly occupational therapists, to meet the challenges posed by this opportunity.

Intersectoral coordination of service is required to ensure the availability of appropriately focussed services in the Departments of Labour, Social Development and Education. Shifts in emphasis will cast disabled people in the role of worker, albeit one that might require reasonable accommodation. Such a change will reduce the 'otherness' experienced by disabled people and facilitate their participation in work.

Developing supportive employment programmes

New labour legislation now provides the foundation on which supported employment programmes can be developed. Environments for supportive employment are usually set up in partnership with socially conscious businesses. The nature of support offered is determined by the needs of the worker. Support could include on-the-job training, practical problem solving, job analysis and modification, training of fellow employees and liaison between employee and employer. Problems associated with successful implementation of this strategy include employers' resistance towards employing disabled people, particularly people with psychiatric disability. Macro influences, such as high unemployment, add to the difficulty associated with securing supportive employment positions.

9.2.2. The offer of constructive support

For many participants support was a very important facilitatory influence that shaped their lives in a number of significant ways. Even when participants were seemingly unable to find or maintain work, they were able to do so within support structures such as the TEP. Some consideration is needed to explore the nature of support that had constructive outcomes, as opposed to

being perceived as patronising or misplaced. Practical support could be given by anyone, including family and friends. General support at work was provided by co-workers and accommodation in the workplace was made by employers and co-workers. There was however a dimension of support that required a relatively sophisticated grounding in issues of psychiatric impairment, relationships and matching (work) ability with (work) requirements or demands. It was within these dimensions of support that participants were able to work.

Support at work comprised assistance when (1) difficulties had to be resolved, (2) possible solutions to problems considered and (3) the work environment was perceived to be hostile. Such assistance seldom involved the processes or work itself, but focussed on the integration of the person within the work environment. To label such support as 'emotional support' would be an oversimplification. Instead, it required consideration of complex issues that might have contributed to a particular situation. Often, the role of the impairment, or the role of stigma, had to be considered because one or the other (or a combination of the two) might have impacted on the difficulties experienced.

Another important element of support could be labelled 'facilitated disclosure'. This implies support from an external agency in the process of obtaining work (as was the case in supported employment). The key ingredient of facilitated disclosure was that knowledge of the psychiatric impairment was known to all, even before the appointment was made. The important implication (for participants) was that they were judged to be acceptable by an employer with full knowledge of their impairment. Another was that tensions about competence and worth, on the one hand, and the demands of the job, on the other, were shared with a service provider. Facilitated disclosure was found to be hugely beneficial in that it impacted several domains of influence contained in the Model of Participation and Restriction. The domain most obviously improved by support was 'empowered by knowledge'; the impact on other domains was that experiences of otherness were resolved,

anticipated stigma was reduced and maintained involvement in work facilitated.

9.2.3. Disclosure to be recommended and assisted

The Model of Participation and Restriction shows that the prominence of attitudinal forces hinder work more strongly than symptomatology. The attitudes of people with psychiatric disability themselves were also shown to interfere with their abilities and intentions to work, particularly when stigma was anticipated.

Feelings of otherness prevailed even when participants were not actively being discriminated against. In fact, participants who were successfully hiding their impairment experienced an even stronger sense of otherness than did participants who disclosed their impairment. The question was whether participants who disclosed were more at ease because they disclosed, or whether participants who felt more at ease chose to disclose. I would argue that disclosure facilitated a sense of comfort and belonging. It brought flexibility that allowed participants to 'absorb' secondary damage associated with having impairment; thereby limiting its negative impact in the life-spaces of participants.

Feelings of otherness, which grew from a sense of alienation, seemed to be resolved through disclosure; disclosure was therefore both a risk and the only mechanism through which a real sense of belonging could be achieved. By risk I mean the fact that stigmatisation was a reality in participants' lives, one that they were trying to manage on a day to day basis. Decisions about disclosure were informed by reasoning that weighed up potential risk and benefits. This was not easily done because neither the risk nor the benefit could really be known before these were actually experienced.

9.2.4. Removal of attitudinal barriers

Recent developments in South African labour legislation emphasise employment equity and set goals to reduce discrimination and to promote redress. The combined impact of new legislation³⁵ contributes to a climate that is less tolerant of barriers that marginalise particular groups and should thus stimulate employment of disabled people, directly or indirectly. Discrimination against people with psychiatric impairment is the main compounding factor that contributes to the experience of disability. As with physical impairments, having a psychiatric impairment can result in the loss of particular abilities. Such losses are usually temporary in nature, with lasting residual loss often being negligible. Yet, fear associated with psychiatric impairment, and expectations of failure seem to surpass that of physical impairment. The reluctance of society to foster the integration of people with psychiatric disability does not seem to be proportional to the loss of ability. Instead, it is informed by fear and misunderstanding.

Attitudinal barriers are best confronted through education when people with psychiatric disability are accommodated within existing work situations. This issue was often overlooked, in part because of a tendency to maintain secrecy, on the part of the person with psychiatric disability, and confidentiality, on the part of the rehabilitation professional. Ambivalence about making a full disclosure to employers and co-workers is something all participants in the research projects struggled with. This was the result of anticipated discrimination.

³⁵ The Employment Equity Act of 1998, together with the Code of Good Practice, the Basic Conditions of Employment Act of 1997 and the Skills Development Act of 1998.

Managing attitudes

Participants were sensitive to comments made, and the behaviour shown by others, particularly in the place of work. Entry into work should be done with care and attention being given to assessing needs for disability education. Employers and co-workers will benefit from education to combat the continuation of negative stereotypes and attitudes about psychiatric disability which prevail in mainstream society. Without such training, one would expect that attitudes towards people with disability will continue to interfere with relationships and prevent an optimal environment being established in the place of work.

Acceptance of psychiatric disability in the disability movement

To achieve an inclusive society people with psychiatric disabilities will need to benefit more from the disability movement from which they have largely been missing. They could benefit from activism that is spearheaded by disabled people's organisations. People with physical, sensory and psychiatric disability will have to learn more about one another in order to find common ground. The reasons given for the marginalisation of people with psychiatric disability include criticisms that people with psychiatric disability do not speak with a unified voice or that they do not fit the conceptualisation of disability as formulated within the social model of disability. It should be clear that roles performed by health professionals should also be expanded beyond clinical- or rehabilitative roles, to include advocacy for the rights of people with psychiatric disability and even activism. Self activism by people with psychiatric disability would however benefit their cause and result in an important sense of agency.

Attitudes of health professionals

Turner proposed an analysis of human and social rights that is grounded in the social ontology of human beings as both frail and vulnerable (Turner, 2001). Training of health professionals increasingly requires a more holistic view of illness and health than was the case in the past. This is the result of re-emphasising Department of Health services and approaches in order to focus on Primary Health Care philosophies. Conceptualisation of disability using non-medical model interpretations was identified as not receiving sufficient attention in health professionals' education by the Health Professions Council of South Africa (HPCSA). This led to an investigation into the content pertaining to disability currently included in curricula for the training of health professionals. An opportunity to broaden the knowledge base of health professionals in South Africa presented itself in the newly allocated function of the HPCSA which requires them to register and accredit qualifications in their capacity as Higher Education Qualifications Committee (HEQC) (under the auspices of the National Qualifications Framework (NQF)). In its capacity as HEQC, the HPCSA will have significant power to directly shape qualifications that are registered for the training of health professionals. Each Professional Board of the HPCSA recently formed a Standard Generating Body that was tasked with the development of 'exit level competencies' for each qualification. Processes utilised to develop such exit level competencies were carefully considered and are regulated to include a broad consultation process in which stakeholders are given an opportunity to make contributions. Qualifications will receive registration for five years only; this is to ensure regular update in a continuous cyclical process. The Social Model of Disability should be promoted as a basic level outcome for all health professional qualifications.

9.3. Recommendations for occupational therapy

9.3.1. Alleviation of occupational justice

The scope of services offered to people with psychiatric impairment should be broadened to include the facilitation of their participation in chosen occupations. The natural life-spaces of participants should become the domain of focus, because it is here that people with psychiatric disability stand to benefit most. Hospitalisation and other interventions that focus on alleviation of symptoms and management of impairment are essential. Participants all relied on correct diagnosis and effective management of the symptoms associated with their impairment. This is however merely the foundation for integration back into their respective communities.

It is immediately problematic to expect broader, and more sophisticated, services when some people with psychiatric disability do not even receive the most basic care. I therefore argue that decisions about service delivery and decisions about strategies that will foster participation in work should be made against the background of equity as a current foundational principle in South Africa. The achievement of equity, in terms of service delivery, would be more difficult to gauge than would equality. However, the principle of justice is inherent in the achievement of equity. The benefits of using equity as a standard within the South African context are obvious; it would be difficult to argue against it. People with psychiatric impairment should no longer be neglected in terms of adequate services not being made available to them.

Rehabilitation professionals, with good knowledge of psychiatric impairment, would be best suited to assist with the process of helping to find employment. This is because of the complexities inherent in judging ability and potential

performance and matching these with job demands and with participants' future vision. Participation in environments that are not congruent with participants' own work vision does not have a positive impact on the process of identity construction. Instead it confirms many of the negative stereotypes that society holds about people with psychiatric disability. However, some of the required responsibilities could be carried by less expensive practitioners, for example job coaches. This would allow for a better spread of services to reach more people who need assistance. The sophistication of knowledge required would however suggest that such practitioners be encouraged to work under the guidance of an occupational therapist.

9.3.2. The process of recovery

Recovery as a process was not included in the model but was a pertinent issue for consideration throughout the research process. Recovery was obviously linked to the issues presented in the model, but it was understood to be a different and separate process. The notion of recovery actually stood apart from the other processes of healing and rehabilitation – and also from participation in work. The concept was used by people with psychiatric disability themselves to explain their own process of recovery that might have been related to neither treatment nor work. People with psychiatric disability define recovery for themselves, and therefore hold the power to determine both the process and the progress of recovery.

Recovery, described as a life-long process, could be in progress even while some symptoms prevailed. A path of recovery was in part determined by the participant, in part by significant others and in part by the context. The direct impact of impairment seemed to be the influence that complicated participants' recovery because of the unpredictable nature of psychiatric impairment and the power it had to change the revealing of identity.

Recovery is a deeply personal journey that does not rely on the impairment being 'cured'. Anthony explained that the concept involves much more than recovery from the impact of illness, it also includes recovery "from the stigma they have incorporated into their very being; from the iatrogenic effects of treatment settings; from lack of recent opportunities for self-determination; from the negative side effects of unemployment; and from crushed dreams. Recovery is often a complex, time-consuming process" (Anthony 1993b:11). Yet such understandings of recovery have yet to be implanted in occupational therapy, because of the importance assigned people with psychiatric disability's own understanding of what is good for them. It might also press for a bigger focus on occupation in natural environments – even before all symptoms have disappeared.

More respect should be given to people with psychiatric disabilities' intentions to facilitate their own recovery. This is something that they do within their own realm of experience and within their own needs. When rehabilitation aspects are over-emphasised, this might reduce participants' own belief, commitment and awareness of their own recovery. Conversely, a better understanding of recovery as a process with inherent power to facilitate wellness would equip rehabilitation professionals better to work alongside people with psychiatric impairment during such a process.

9.4. Recommendations for changes in legislation

Over the last decade much energy and attention went into the development of cutting-edge legislation designed to bring South African society closer to the ideal of an inclusive society. Employers are expected to play a role in the establishment of disabled people in work. Legislative guidelines assigned responsibility, whilst tax incentives might provide additional motivation for employers to play a more significant role. The stumbling blocks that remain are employers' lack of awareness of some workers' disabilities, lack of

understanding of employers' unique perspectives and motivations in the vocational rehabilitation process and misconceptions about the role disabled people wish to play in work. Strategies that will improve communication and that will allow for decisions to be made jointly among all parties is needed in order to bridge these and other gaps.

9.4.1. Examples for the Code of Good Practice

Of particular interest is an understanding of barriers that work against the achievement of employment equity. Information obtained in this study could thus be used to facilitate more effective implementation of new labour legislation. The Code of Good Practice (CGP) (Department of Labour 2001), in particular, lacks detail with regards to useful suggestions for people with psychiatric disability. In contrast, strategies for accommodating people with physical disability are currently more detailed and comprehensive.

9.4.2. Safeguarding work at time of relapse

Decisions that were made during relapse, which were motivated directly by the psychiatric illness, should not be allowed to have a lasting negative impact on people with psychiatric disabilities' maintained involvement with work. This aspect needs careful consideration in order to be included as a part of the CGP that was written to guide the implementation of the Employment Equity Act (Department of Labour, 1998). A strong recommendation is made that a professional with good knowledge of psychiatric impairments should act as a consultant when the Commission for Conflict, Mediation and Arbitration (CCMA) considers cases that involve workers with psychiatric disability. When workers have lost their jobs due to symptoms associated with psychiatric impairment, or when other conflicts arise in the workplace, expert knowledge

is required. Such knowledge would have to include the impact of psychiatric impairment on work and knowledge of the relevant legislation.

9.5. Recommendations for future research

In the absence of research findings obtained from exploring the experiences of South Africans with psychiatric disability, service providers can only speculate about the barriers that hinder or prevent work participation. Quality information, applicable in the South African context, is required to guide practice. More research is needed that explores disability and work in developing countries.

Lincoln (1992) argued for the place of qualitative and constructivist research in policy decisions. She uses a trend that she observed in the USA as a basis for her argument, explaining that policy decisions are usually based on majority views; not taking cognisance of minority views. Whilst these concerns do not directly apply to the global South African situation, and majority concerns are being addressed for the first time, these do apply to the position of people with psychiatric disability as a minority and marginalised subgroup in the disability sector. The focus of proposed solutions tends to be on people with physical disability – there is seemingly a limited understanding about the special needs of people with psychiatric impairment. They are being left behind during an era of transformation in which redress is hailed as the overarching and most important guiding principle. The reasons for such an ‘oversight’ should be explored, but one might be the current prioritisation of race, then gender above disability. One reason for the low priority would thus be that people with disability are a minority group whose needs are currently overridden by majority concerns.

9.5.1. Exploring the impact of disclosure

Disclosure of psychiatric impairment emerged as the one strategy through which participants were able to 'manage' their sense of otherness and experiences of alienation. Research to explore patterns of disclosure, together with the possible impact of such patterns on the ability to work, would be of benefit. Such knowledge would inform people with psychiatric disability and service providers; it could guide decisions about disclosure.

9.5.2. Attitudinal barriers in the workplace

Current research in which the barriers faced by disabled people were explored originated in contexts that are different from the South African context. Research should be done within the South African context in order to inform practice here.

People with psychiatric disability were shown to be up against attitudinal barriers. Such barriers that prevent entry into the world of work should be explored and understood. Research aimed at exploring this issue would best be done from the perspective of potential employers and co-workers.

9.5.3. Prevalence of influences on work participation

The influences that had an impact on tendencies of people with psychiatric disabilities to restrict their involvement in occupations, or to participate in such occupations, were depicted in the Model of Participation and Restriction. Research might be done to determine the prevalence (and frequency) of these impacts amongst people with psychiatric disabilities. Such information would further inform service delivery and might add the urgency required to adequately bring redress.

9.5.4. Testing and development of the Model of Participation and Restriction

Research to explore the domains of influence that were found to shape participation in work needs to be done. Such research might also explore;

- ◆ the assumptions made that each of the identified domains of influence impacts on participation in work,
- ◆ the assumption that change can be facilitated within each of the domains of influence,
- ◆ strategies through which such change might be brought about,
- ◆ whether such changes in fact do influence participation and
- ◆ whether it could be developed into an assessment tool that might inform practice.

9.5.5. The use of evidence-based practice

The use of evidence based practice was proposed by Davis and Rinaldi who incorporated it into their work to promote the participation of people with mental illness in work (Davis and Rinaldi, 2004). The quality and quantity of evidence exploring work for people with psychiatric disability has grown over the last decade, thus making evidence based practice a viable option. For example, supported employment has been shown to be a more effective strategy through which work outcome is achieved. Current vocational rehabilitation practices should be scrutinised for their effectiveness in facilitating work. When the effectiveness of interventions cannot be verified by evidence, resources might have to be reallocated to services that are found to be effectively addressing work. However, attention would have to be given to the applicability of evidence in the South African context.

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Appendix I: GLOSSARY OF TERMS

Occupation, Work and Productivity

WORK: A goal-directed activity that produces something of acknowledged value

EMPLOYMENT: The state of being commissioned to work for another in return for remuneration.

OCCUPATION: "Chunks or units of culturally and personally meaningful activity within the stream of human behaviour" (Yerxa, Clark, Frank, Jackson, Parham, Pierce, Stein and Zemke, 1990). "Occupation is most often defined as work, play, leisure, and self-maintenance. Each of these abstract units can be divided into concrete occupations (Henderson, 1996).

COMPETITIVE EMPLOYMENT: Jobs that "have permanent status, pay at least minimum wage, and are not set aside for people with disabilities, that is, anyone can apply" (Salyers et al., 2004:302).

OPEN LABOUR MARKET: Jobs within regular work environments that are not set aside for people with disabilities, anyone can apply.

SHELTERED EMPLOYMENT or PROTECTED EMPLOYMENT: Work opportunities that are set aside for people with disabilities. Government subsidy is available for the maintenance of such programmes. Remuneration for work is negligible, to allow for continuation of disability benefits.

LIFE-SPACE: Those natural contexts in which people regularly participate in occupations.

Disability, Impairment, Health and Wellness

DISABILITY: "In our view it is society which disables physically impaired people.

Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society (Oliver, 2004:19 citing UPIAS 1976:14).

DISABILITY (AS DEFINED FOR PURPOSES OF THE EEA): The scope of protection for people with disabilities in employment focuses on the effect of a disability on the person in relation to the working environment, and not on the diagnosis of the impairment.

Only people who satisfy all the criteria in the definition:

- (i) long-term or recurring;
- (ii) having a physical or mental impairment;
- (iii) which substantially limits,

are considered as persons with disabilities (EEA, Department of Labour 1998:7).

MENTAL IMPAIRMENT (AS DEFINED FOR PURPOSES OF THE EEA): A "clinically recognised condition or illness that affects a person's thought processes, judgment or emotions" (EEA, Department of Labour 1998:8)

Biography and Interpretive Biography

BIOGRAPHY: A written account or history of the life of an individual. The art of writing such accounts (Denzin 1989:10).

INTERPRETIVE BIOGRAPHY: Creating literary, narrative, accounts and representations of lived experiences. Telling and inscribing stories (Denzin 1989:11).

Variations of truth and fact

FACTS: Events that are believed to have occurred or will occur, i.e. the date today (Denzin 1989:23).

FICTION: A narrative (story, account) which deals with real or imagined facts and facticities (Denzin 1989:23).

FACTICITIES: Describe how facts were lived and experienced by interacting individuals (Denzin 1989:23).

REALITY: The "objects, qualities or events to which true ideas are" directed (Peirce, 1958:74 in Denzin 1989:23).

Variations of interpretation and knowing.

INTERPRETATION: The act of interpreting and making sense out of something, creates the condition for *understanding*, which involves being able to grasp the meanings of an interpreted experience for another individual.

INTERSUBJECTIVE KNOWING: Shared experiences and the knowledge gained from having participated in a common experience with another person (Denzin, 1984a:133 in Denzin, 1989:28).

OBJECTIVE KNOWING assumes that one can stand outside an experience and understand it, independent of the persons experiencing the phenomenon in question (Denzin, 1989:27).

SUBJECTIVE KNOWING involves drawing on personal experience or the personal experience of others in an effort to form an understanding and interpretation of a particular phenomenon (Denzin, 1989:27).

TRUTH: Statements that are in agreement with facts and facticities as they are known and commonly understood "within a community of minds" (Peirce, 1959, Volume 8, p. 18 in Denzin, 1989:23).

CULTURE: A "set of beliefs, norms and values that have value and shape the networks in which human interactions take place" (Moldavsky, 2004:36).

CULTURAL IDENTITY: The "culture with which someone identifies and looks for standards of behaviour" (Moldavsky, 2004:36).

ETHNICITY: A "group of individuals sharing a sense of common identity, ancestry, beliefs and history" (Moldavsky, 2004:36)

Discrimination and Equity

ECONOMIC DISCRIMINATION occurs when two groups of workers with equal average productivity have different average wages or opportunities for employment (Baldwin and Johnson, 1998:41)

Appendix II: Consent form in Afrikaans

TOESTEMMING

Doel: Deur hierdie studie te doen beoog ek om meer te leer van die invloede wat positief en negatief inwerk op mense met 'n psigiatriese diagnose se vermoë en geleenthede om te werk. Ek hoop om uiteindelik hierdie inligting te gebruik om diskriminasie teen te werk. Hierdie studie sal geheel en al gerig wees op die ervaring en opinies van verbruikers van psigiatrie dienste.

Indien u sou toestem om deel te neem sal dit die volgende behels:

- Onderhoudvoering. Die onderhoude wat met u gevoer word sal opgeneem word ten einde 'n record te behou van presies wat u gesê het. Sodoende word kan u woorde nie vergeet of verdraai word nie.
- On u ervarings te deel. Ek stel belang om te leer van u ervarings rondom werk en u opinies omtrent uself as 'n werker.
- Om my interpretasie en afleidings te toets en/of te kontroleer. Na die eerste onderhoud sal ek u weer kontak. Indien u sou instem om my weer te sien sal ek graag van die geleentheid gebruik maak om verder te gesels, idees wat voortspruit vanuit die vorige onderhoud met u deur te praat en my interpretasie van wat u met my gedeel het aan u voor te le vir bevestiging.

Ek,, stem hiermee in om deel te neem aan die projek onder die volgende voorwaardes:

- Dat alle inligting konfidensieel en privaat sal wees. My naam sal nie gebruik word nie en geen identifiserende inligting sal bekend gemaak word nie.
- Ek behou die reg om te vra dat die bandopnemer afgeskakel word.
- Ek behou die reg om te onttrek uit die study.
- Ek mag getranskribeerde onderhoude sien en veranderings aanbeveel ten einde die akkuraatheid en duidelikheid daarvan te verbeter.
- Ek is bewus dat die bevindinge van hierdie studie bekend gemaak gaan word as 'n verslag, 'n voordrag- of 'n publikasie.

Appendix III: Consent form in English

CONSENT FORM:

Purpose: Through doing this study, I hope to learn about the influences that hinder or assist people with mental illness to work. I hope to develop information that will be used to remove discrimination. The study will be based on the experience of people with mental illness.

If you agree to participate, it will involve the following:

- To be interviewed. These interviews will be tape recorded to keep a record of exactly what you said. This will ensure that nothing is missed, and also that your words are not changed or misunderstood.
- To talk about your experiences. I am interested hear your experiences related to work and being a worker.
- To check and/or clarify my understanding of what you said. After the first interview I will contact you again. If you agree to see me again, we could use the opportunity to talk some more, clarify or confirm what you said during the previous interview(s), or point out misunderstandings.

I, agree to participate

in this research project under the following conditions:

- Confidentiality and privacy will be protected. No mention will be made of my name, or any other identifying information when the findings of the study is reported
- I could ask for the tape recorder to be switched off at any time.
- I am allowed to withdraw from the study.
- I have the right to review transcripts of the interviews and to suggest changes for accuracy or clarity.
- I am aware that findings from this study will be reported in the form of a report, presentations and publications.

Appendix IV: Consent form in isiXhosa

I-fomu yokuzibophele a

Isizathu: Ngokwenza le mfunalwazi ndinethemba lokufunda malunga nokuthintela okanye okukhuthaza abantu abagula ngokwasengqondweni ukuba basebenze. Ndinethemba lokuza nolwazi oluzakunceda ukuphelisa ucalu-calulo. Imfunalwazi izakubamalunga nobomi babantu abagula ngokwasengqondweni.

Ukuba uyavuma ukuthatha inxaxheba izakube ingoluhlobo:

- Uzakubuzwa imibuzo. Le mibuzo izakurekhodishwa nge tape ukuze kugcinwe yonke into oyithethileyo ngohlobo olululo. Loo nto iyakuthetha ukuba ayikho into ephosakeleyo kwaye amazwi akho awaguqulwanga okanye aviwe ngenye indlela.
- Uthethe ngawe: Ndinomdla wokuva ngawe malunga nomsebenzi wakho nokuba ngumsebenzi.
- Ndiqondise okanye ndicacise indlela endikuve ngayo izinto obuzithetha. Emva kwendibano yethu yokuqala ndizakuphinda ndinxulumane nawe. Ukuba uyavuma ukuphinda udibane nam, singayisebenzisa loo nxaxheba yokuba siphinde sithethe, ndicacise ndiqinisekise ubukuthethile kwindibano yangaphambili okanye sijonge izinto endingaziqondanga kakuhle.

Mna....., ndiyavuma ukuthatha inxaxheba kule mfunalwazi phantsi kwalemiqathango:

- Ndizakukhuseleka kungabikho waziyo ngam. Igama lam alizukusetyenziswa, okanye nantoni eyakuthi indazise xa iziphumo zalemfunalwazi zichazwa.
- Ndingacela ukuba itape recorder icinywe nangaliphi na ixesha.
- Ndivumelekile ndiyeke nanini ukuthatha inxaxheba kulemfunalwazi.
- Ndinelungelo lokuhlengahlengisa okubhaliweyo ngalemfunalwazi kwaye ndicebise ukuba kukho into efuna ukutshintshwa apho kufunuka khona.
- Ndiyayazi into yokuba iziphumo zalemfunalwazi ziyakuchazwa kwi-report, kuthethwe ngazo zize zishicilelwe.

Isayinwe:.....

Umhla:....../...../20