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**Psychosocial Rehabilitation**  
**for people with mental illness**  
**in the South African Context:**  
**An evaluation from a service-users perspective.**

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for the award of the degree of Master of Arts in Clinical Psychology

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## COMPULSORY DECLARATION

This work has not been previously submitted in whole, or in part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other people has been attributed, and has been cited and referenced.

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## **Abstract**

The aim of this study was to explore perceived significant changes in the quality of life of people with mental illness accessing psychosocial rehabilitation programmes. Furthermore a comparison was drawn between the outcomes experienced by these service-users and the vision and aims of Cape Mental Health Society's programmes. These included the Fountain House clubhouse model, community-based support groups, supported housing and a self-advocacy body.

The aim of psychosocial rehabilitation as an empowerment model is that service-users gain improved functioning, an increase in social functioning and an enhancement of their subjective quality of life. Embedded in these programmes is the provision of safe spaces, where meaningful interactions with others in shared activities occur. This contributes to skills development, social competence and the building of a positive sense of self, which is in line with principles of the recovery paradigm. Few such services exist in Cape Town, South Africa and no relevant studies have been documented.

A qualitative participatory approach was used utilising focus groups on two levels: first in mapping the territory and defining outcomes according to service-users; and secondly, for data collection of lived experiences of participants. The "most significant change technique", a process which involves the collection of stories of subjective change, was used to focus the group processes. All groups were digitally recorded and transcribed. Data was examined according to a basic method of thematic analysis and participants' stories were classified according to broad domains of social, personal, learning, work, and living. A total of 44 service-

users from the four Cape Mental Health Society programmes, all diagnosed with severe mental illness, from varied demographic backgrounds and levels of functioning participated in nine focus groups.

Participants felt that in attending the programmes they had experienced improved interpersonal connection, interaction and activity. This then seems to indicate some process of reclamation and recovery in the face of the loss of meaningful relationships when becoming ill with a mental illness. The positive benefits experienced by participants in the supportive community offered by the programmes, seem to be in line with programme objectives. The findings support the importance of opportunities for participation in valued meaningful activities, within a social context. Participants felt that by attending the programmes they benefitted on a personal level, building a positive sense of self, which included increased confidence and self-esteem, gaining hope, improved positive attitude, self-knowledge and acceptance, increase in motivation, increased vitality, increased motivation, increased awareness and interest in life, and gaining a sense of purpose and meaning.

Subjective quality of life improvements for most participants in this study included an improved positive sense of self as well as valued socialization experiences, confirming the importance of these factors in recovery. The Cape Mental Health Society psychosocial rehabilitation programmes are accordingly robust in nature. In line with the philosophy of psychosocial rehabilitation and recovery principles, the programmes seem to be providing safe spaces for people with mental illness, creating opportunities for meaningful interactions with others,

thereby enhancing the confidence and self-esteem of participants while, at the same time building social skills.

**Key Words:** mental illness; psychosocial rehabilitation; most significant change; quality of life; recovery; participatory research

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## **CHAPTER 1: INTRODUCTION**

### **1.1 Introduction**

The World Health Organization has urged countries to give priority to mental health in their health planning. It estimates that 25% of all people are affected by mental and behavioural disorders at some time during their lives, thus impacting economically on societies and on the quality of life of individuals and families (World Health Organization [WHO], 2001). The high estimated life-time prevalence and relatively early onset of psychiatric disorders in South Africa underline the urgent need to address the problem (Stein et al., 2008).

The World Health Report 2001 (WHO, 2001) emphasises that comprehensive community health services need to follow de-institutionalisation. In South Africa, the policy of de-institutionalisation and a continued reduction of beds in psychiatric hospitals have highlighted the urgency of directing maximum effort to ensuring that people with mental illness have access to services that will ensure best possible functioning within their communities, and reduce the need for re-admission. The study of Sandler and Jakoet (1985) noted a rise in re-admission rates since the implementation of de-institutionalisation policies.

New psychotropic medications (which provide improved symptom control) and research-based intervention strategies support the growing realisation that a large percentage of people with mental illness may be able to recover and live satisfying lives of quality (Stromwell & Hurdle, 2003). However, the devastating effects of an initial breakdown and the then (often) long road to identify the medication that is a best-fit must not be underestimated and the need for a recovery model is clear. The first couple of years after initial diagnosis are acknowledged to be the crucial stage for intervention, as losses accumulate during this period (Craig, 2006). Damage to self-esteem, loss of social networks and loss of opportunities for education and employment all add to the downward drift of people with mental illness in society.

The Health Care 2010 Plan of the South African Department of Health marks a shift towards the provision of services at community level, as opposed to hospitalisation. The Mental Health Care Act No. 17 of 2004 emphasises that people with mental illness have the right to rehabilitation services. Psychosocial Rehabilitation (PSR) is the Western Cape Department of Health's

preferred method of treatment; however, though several policies have been developed regarding the implementation of PSR, limited funding is given to these kinds of programmes. There are also no published research studies on the effectiveness of PSR in the South African context.

In light of the high estimated life-time prevalence of mental illness in South Africa, as noted in Stein et al. (2008), it is vital that people with mental illness have access to services that improve their quality of life and minimise the disabling effects of their illness. The significant under-funding of mental health services restricts the implementation of programmes for people with mental illness. These are provided mainly by the NGO sector, whose resources are seriously over-extended due to insufficient subsidies. This state of affairs flies in the face of the promises made by national and provincial policies, which support and advocate the right of people with mental illness to access rehabilitation services.

The significance of this study lies in the documentation of a provision of service that is beneficial to people with mental illness. It provides evidence to support appropriate funding for mental health services.

The PSR programme under investigation is unique in South Africa, due to its comprehensive continuum-of-care model. In Cape Town, where this programme operates, few services are available for people with mental illness. The Cape Mental Health Society (CMHS) is a registered non-profit organisation that provides a comprehensive Psychosocial Rehabilitation (PSR) programme for adults with severe mental illness, to facilitate opportunities for the improvement in functioning necessary for integration into community life. The Society's vision and mission for all its PSR programmes speaks of the "highest possible level of mental health and quality of life" as its aim for programme participants (Cape Mental Health Society, 2007). The PSR programme – according to PSR principles – focuses on strengths and abilities, rather than disability or therapeutic insight (Anthony, Cohen, & Farkas, 1982; Anthony, Kennard, O'Brien, & Forbes, 1986; Stromwell & Hurdle, 2003). The CMHS PSR programme consists of four sub-programmes, namely, the Fountain House clubhouse model; community-based support groups (Rainbow Foundation); supported housing (Kimber House); and a self-advocacy body (Cape Consumer's Advocacy Body). A total number of 650 people with mental illness are service-users

of these programmes. The programmes operate from Observatory, where Fountain House is situated.

Fountain House (SA) is a structured vocational training programme, based on the international clubhouse model, in which members (service-users) work alongside trained rehabilitation workers, thus contributing to the effective running of the programme. It is understood to build confidence, and increase self-esteem and self-worth. Fountain House is open every weekday from 8.30am until 4.30pm, and consists of four units: catering, administrative, a paper-making workshop, and the employment unit. The programme aims to provide a safe and secure space, with meaningful activities, in order to improve members' work and social abilities.

Fountain House provides programme activities in four life areas of PSR:

- Objectives in the life area of work include the individual's acquisition of appropriate work skills and the development of specific vocational skills, to enhance the individual's basic efficiency and capacity as a worker and to secure employment opportunities.
- Objectives in the life area of learning include increasing the individual's knowledge of and insight into his or her illness; improved coping skills; attainment of functional skills in various areas; and personal empowerment, through participation in decision-making processes and in taking responsibility and ownership of his or her own life and recovery.
- In the life area of socialisation the aim is to offer a social and recreational programme, to ensure the acquisition of appropriate social skills.
- The life area of living is composed in part of many poverty alleviation initiatives, addressing needs of transport, food and disposable income (Cape Mental Health Society, 2009). This life area also addresses housing needs in the form of supported housing (Kimber House).

Kimber House is a group home in Observatory, currently housing five females and six males. It offers a "safe, secure, comfortable, supportive and affordable home environment" to members of Fountain House (Cape Mental Health Society, 2007).

From Fountain House premises in Observatory, rehabilitation workers visit communities where the Rainbow Foundation (which consists of sixteen community-based support groups) provides services within the communities where service-users live. The Rainbow Foundation aims to

promote adjustment to community living through skills development, educational activities concerning knowledge about mental illness, income-generating ventures, and the development of social support networks (Cape Mental Health Society, 2007). A key objective is to offer social support and opportunities for socialisation. This is achieved through community-based group meetings held weekly, bi-weekly or monthly at various community facilities in disadvantaged communities in the greater Cape Town area.

The Cape Consumer's Advocacy Body (CCAB) has a general monthly meeting at Fountain House, but the Executive Committee (ExCo) meets weekly. This group of consumers is the 'voice' of people with mental illness. They represent service-users on various forums, and part of their task is to raise issues pertaining to service-users. They also educate service-users, service-providers and the public concerning the rights and responsibilities of service-users.

The researcher was familiar with the psychosocial rehabilitation model because of her experience as a rehabilitation worker at Fountain House. This model seemed to respect the persons involved, and was a move away from the model of an expert applying treatment. Improvements in peoples' conditions were clear to see. For example, a person who had just sat in a corner for months slowly began engaging with others, initially only by way of a smile, but progressing to a point at which conversations could be sustained. How to record successes was a key challenge. Balanced score-cards, with objectives (accompanied by the activities needed to meet these objectives), measurement tools and targets became the management tool for monitoring the programme activities and outcomes. Targets were set for numbers of members participating in each activity, and attendance lists were devised. 'Improved functioning' was the definition of a successful outcome, but how to quantify this was the challenge. In addition, statistical results can never capture the rich personal experience of each member's individual journey to recovery. What changes do they experience?

## **1.2 Research Objectives**

This investigation looked at the relationship between the service provided for people with a mental illness, and the outcomes experienced by service-users. The main research question concerns the 'robustness' of the psychosocial rehabilitation programme presented by the Cape Mental Health Society in Cape Town, South Africa, for people with mental illness. How

beneficial is psychosocial rehabilitation (PSR), otherwise known as psychiatric rehabilitation, to people with mental illness? A more focused question is as follows: Are the vision and aims of PSR, as adopted by this programme, reflected in the lived experiences of the service-users? And what are the changes that service-users experience, and are these in line with programme objectives?

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## **CHAPTER 2: LITERATURE REVIEW**

### **2.1 Living with mental illness**

Mental illness is often accompanied by severe psychosocial dysfunction, including impairment due to positive and negative affective and cognitive symptoms, adverse psychological reactions to the illness, and the distress caused by the impairment (Craig, 2006; Luk & Shek, 2008).

Altered perceptions (including hallucinations and delusions), impaired concentration and attentional deficits – as well as a lack of energy and motivation – undermine the individual's ability to cope, to respond appropriately to the external world and to be involved in life in general in a meaningful way (Craig, 2006; Starkey & Flannery, 1997). Decreased future planning and consequent diminished goal-directed behaviour (due to the negative symptoms and cognitive impairments) add up to lesser quality of life (Glynn, 2003). The impairment caused by the symptoms leads to feelings of loss of a sense of control, and failure to master the environment (Starkey & Flannery, 1997). The struggle to perform the tasks of daily living, such as household management, functioning at work and self-care, as well as decreased social skills, all contribute to the disability of a mental illness and induce a helplessness in people with mental illness (Craig, 2006; McReynolds, 2002; Starkey & Flannery, 1997). Chovil (2005), a service-user-writer, describes a loss of functioning or an inability to participate in a competitive world, especially during a time when “one's place in the world is being defined” (p. 408). Mental illness has a profound impact on quality of life, especially on the ability to participate in and have access to educational and vocational opportunities, financial independence and healthy relationships (Michalak, Yatham, Kolesar, & Lam, 2006).

Craig (2006) describes how stigma leads to exclusion from social roles, and handicaps a person with mental illness from accessing opportunities of meaningful activity within the community. This alienation of a person with mental illness restricts their integration into the community, as well as limiting their experiences of mastery (Luk & Shek, 2008; Sayce, 2000; Starkey & Flannery, 1997). Isolation and marginalisation as a result of stigma have a profound effect on the individual already struggling with mental illness. According to Herman, Onaga, Pernice-Duca, Oh and Ferguson (2005), many such people live lonely lives, with very little social or recreational activity. Stigma affects an individual's self-esteem, as he or she feels inferior to

others and is an outsider to the experiences of shared humanity. This process of ‘othering’ – being seen as different – and discrimination through stereotyping, as well as low expectations regarding future success, saturate the experiences of people with mental illness; they erode the sense of belonging to a community, as well as leading to negative self-appraisal which impacts on self-esteem (Corring, 2002; Kahng & Mowbray, 2005; Onken & Slaten, 2000; Pierce, 2004; Smith, 2000). Walsh (1996) feels that these processes can scar an individual, preventing the complete restoration to their former level of functioning. In fact, trauma models support the notion that there can be no return to former functioning, as mental illness changes a person irrevocably.

Social withdrawal is described not only as a negative symptom, but also as a coping mechanism against increasing social anxiety. However, disuse of social skills through a lack of participation in reciprocal social interaction causes the individual to lose his or her social skills and social competence, which increases social anxiety, erodes self-confidence and self-esteem and leads to further withdrawal of interest in the outside world (Chovil, 2005; Starkey & Flannery, 1997). The person becomes increasingly isolated, losing all social connection and thus any possibility of social support. Starkey and Flannery (1997) describe the loss of attachment as a major consequence of schizophrenia - forming and maintaining social relationships being difficult due to faulty interpretation of social cues.

This reduced ability to relate to people and to communicate, to express appropriate emotion, and to manage social stressors, further alienates the sufferer from having a sense of being part of society, and leads to social isolation (Chovil, 2005; Hensley, 2002; Starkey & Flannery, 1997). Two studies on personal loss from mental illness found that loss of social relationships, social support and routine, as well as valued social roles, were strong themes identified in the narratives of people with mental illness (Michalak et al., 2006; Stein, Dworksy, Phillips, & Hunt, 2005). Most individuals with mental illness lack people skills; whether they have lost these social skills or have simply never acquired them, interpersonal situations present them with various challenges (McReynolds, 2002).

Psychological reactions include loss of self-esteem and confidence (often induced by a sense of shame because of devaluation by others), as well as helplessness and a loss of hope and meaning

(Craig, 2006; Luk & Shek, 2008; Michalak et al., 2006; Onken & Slaten, 2000; Ridgway, 2001; Townsend & Glasser, 2003; Walsh, 1996). According to Onken and Slaten (2000), shame has a profound negative influence on identity and intimacy. In a study by Michalak et al. (2006), narratives of people with Bipolar Mood Disorder reported the loss of their sense of self, including subjective feelings about themselves regarding identity loss and reduced self-worth. Loss of a former whole 'normal' self, including a loss of feelings of positive well-being associated with mastery, life purpose and a sense of a future (including a future self that the person might have become if their path had not been interrupted by mental illness) were some of the losses recorded in the narratives of people with mental illness (Piat, Sabetti, & Couture, 2009; Schiff, 2004; Stein et al., 2005).

Ridgway's (2001) narrative analysis of the professional writings of four 'recovered' service-users confirm these previous findings of a loss of hope and future dreams, loss of self-esteem and the sense of self as a unique personality with strengths, together with a profound sense of alienation and extreme social withdrawal.

Medications have improved, but no cure or prevention exists that will eliminate the suffering experienced by people with serious mental illness. Recovery seems possible for some, but even in these cases it may occur only after a 15- to 35-year struggle (Hensley, 2002). The personal experience of many people with mental illness is that of impairment, due to the symptoms as well as the disability that follows, accompanied by feelings of hopelessness, despair and loss of control (Torrey, Rapp, Van Tosh, McNabb, & Ralph, 2005). According to Torrey et al. (2005) the incidence of suicide among people with mental illness reflects this loss of hope.

In his review of narratives of people with mental illness, Davidson (2003) concluded the following:

“Recovery appears to involve minimizing, managing, or overcoming the effects of being a mental patient, including but not limited to, rejection from family, peers, and society as a whole; poverty, unemployment, and substandard housing; loss of valued social roles and identity; loss of sense of self as a an effective social agent and that of purpose and direction associated with it; and a loss of control over, and responsibility for, one's major life decisions” (p.57).

## 2.2 The recovery paradigm

The concept of recovering from a mental illness, or being in recovery despite the disabling effects of the illness, does emerge from the narratives of people with mental illness who were able to rebuild their lives (Jacobson, 2001; Ridgway, 2001; Russinova, 1999). Adding strength to this developing discourse is evidence from research studies supporting the fact that individuals may be able to recover from severe and persistent mental illness, and live satisfying lives with minimal impairment – in contrast to the predictions made (at diagnosis) of chronic illness and inevitable decline. Harding, Brooks, Ashikaga, Strauss, & Breier (1987) established that people with schizophrenia improve significantly over long periods of time in the domains of symptom management, self-care, work, and social relationships. Twenty-five to sixty-five percent of people diagnosed with mental illness will improve significantly over time (often after years of disability), resulting in outcomes ranging from mild impairment to full recovery (Davidson, Harding, & Spaniol as cited in Davidson, Drake, Schmutte, Dinzeo, & Andres-Hyman, 2009).

In contrast to the deficit approach, which has a treatment priority of regulating symptoms and attempting to avoid relapse, the recovery perspective focuses on the augmentation of the person's existing strengths and skills, in order to allow participation in meaningful activities, fostering a more positive sense of self (Russinova, 1999). According to Anthony (1993), recovery is

“a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by the illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness" (p.16).

‘Recovery’ does not mean ‘cure’, but is understood to be a significant improvement or positive change in a person's life (Russinova, 1999). The focus is on living a personally meaningful life within a community (Anthony, 1993).

Recovery is a unique personal process; various definitions exist in the literature. The following concepts seem to be common to experiences of recovery:

- reclaiming hope (Anthony, 1993; Bond, Salyers, Rollins, Rapp, & Zippel, 2004; Craig, 2006; Davidson et al., 2009; Deegan, 1988; Glover, 2005; Herman et al., 2005; Jacobson, 2001; Mead & Copeland, 2000; Ochocka, Nelson, & Janzen, 2005; Onken et al., 2007; Pierce, 2004; Ralph, & Cook, 2007; Ridgway, 2001; Russinova, 1999; Townsend & Glasser, 2003; Walsh, 1996);
- building a strong support system, social connection and reciprocal relationships (Deegan, 1988; Glover, 2005; Herman et al., 2005; Jacobson, 2001; Jenkins & Carpenter-Song, 2005; Mead & Copeland, 2000; Michalak et al., 2006; Ochocka et al., 2005; Onken et al., 2007; Ridgway, 2001; Sells et al., 2004; Smith, 2000; Spaniol & Gagne, 1997);
- building a positive sense of identity, which include aspects such as recovering self-esteem, self-worth, pride, dignity and confidence (Davidson et al., 2009; Deegan, 1988; Jacobson, 2001; Mancini, Hardiman, & Lawson, 2005; Ochocka et al., 2005; Ridgway, 2001; Russinova, 1999; Smith, 2000; Townsend & Glasser, 2003);
- finding a sense of meaning and purpose (Davidson et al., 2009; Deegan, 1988; Glover, 2005; Onken et al., 2007; Ridgway, 2001; Townsend & Glasser, 2003);
- community integration and participation in valued social roles (Davidson et al., 2009; Onken et al., 2007; Sells et al., 2004; Smith, 2000);
- meaningful activities (Herman et al., 2005; Mancini et al., 2005; Russinova, 1999; Smith, 2000);
- self-determination (Bond et al., 2004; Deegan, 2007; Onken et al., 2007; Roe, Rudnick, & Gill, 2007);
- empowerment (Herman et al., 2005; Jacobson, 2001; Spaniol & Gagne, 1997);
- acceptance (Ridgway, 2001; Smith, 2000; Spaniol & Gagne, 1997);
- positive attitude (Ochocka et al., 2005; Smith, 2000);
- developing agency (Glover, 2005; Onken et al., 2007);
- self-efficacy (Bond et al., 2004; Onken et al., 2007);
- knowing your illness and managing symptoms (Deegan, 1988; Jacobson, 2001);
- development of coping skill (Onken et al., 2007);
- negotiating personal space (Sells, Stayner, & Davidson, 2004);

In the qualitative study of Mancini et al. (2005), fifteen leaders in the consumer service-provision group, when asked what assisted their recovery, identified supportive relationships, meaningful activities (e.g. opportunities to grow and develop, taking risks and learning skills), as well as effective treatments, as being essential to their recovering from serious mental illness. These factors helped them to develop self-worth, confidence, meaning, purpose and hope. Strauss (as cited in Mancini et al., 2005) interviewed 66 people with mental illness, and found that a reconstruction of a sense of a competent self is crucial. In his review of 60 narratives of people who recovered from mental illness, Jacobson (2001) found hope, empowerment and connection to be important ingredients of recovery, as well as a supportive community and protection of human rights.

Ridgway's (2001) narrative analysis of the professional writings of four 'recovered' service-users emphasises hope, engagement and participation in life and valued activities, achieving understanding and acceptance, sense of free will and self-control, sense of personal meaning and purpose as well as important human relationships as significant hallmarks of recovery. Resnick et al. (as cited in Piat et al., 2009), in a study based on data from 825 people with mental illness, identified four domains important to recovery: empowerment, hope, knowledge and life satisfaction.

In his analysis of 10 interviews with people with mental illness, Smith (2000) identified the following critical factors in the recovery process; medication; social support; meaningful activities; autonomy; determination; positive attitude. Positive life changes on a personal level for participants in the study of Ochocka et al. (2005) were those of increased self-confidence, assertiveness, independence, self-care and more control over treatment, while on a social level, improved relationships and community involvement were important. Schiff (2004) gives a personal account of what recovery meant for her, which includes "feeling at peace, being happy, feeling comfortable in the world and with others, and feeling hope for the future" (p.215).

Hope is considered to be the crucial cornerstone of the recovery process, and the importance of hope as a vital determinant of recovery emerged strongly in the literature. Recovery, according to service-users, entails a conversion from despair to hope (Anthony, 1993; Glover, 2005; Ridgway, 2001; Russinova, 1999). Hope is conceptualised as taking place within a relationship between

people, and emerges in the presence of trust (Anthony, 1993; Russinova, 1999). Interactions with others can either hinder or foster the development of hope. Initially, hope must be held by another for the person with a mental illness; once it becomes internalised, it is the motivating factor for positive change and participation in new activities, which restore the person's sense of self and provide meaning and purpose (Anthony, 1993; Russinova, 1999).

In her review of the literature, Russinova (1999) found that the learned helplessness often seen in people with mental illness seems to be linked to their contact with mental health practitioners; often they did not provide the person with any hope of recovering or living a life of quality, and sometimes left the person feeling discouraged and disrespected. Ongoing stigma perpetuates this learned helplessness, as it destroys self-esteem and self-determination (Michalak et al., 2006; Walsh, 1996). Becoming an active participant in his or her own life is an important part of a person's recovery (Jenkins & Carpenter-Song, 2005; Ridgway, 2001).

Medication is acknowledged as being critical to recovery for some service-users, insofar as managing symptoms is concerned, but finding the right medication and coping with the side-effects remains a challenge (Smith, 2000). Even with the use of appropriate medication, service-users might still experience residual symptoms. Knowledge of one's illness and how to optimise one's own treatment choices (as well as recognising symptoms in order to feel more in control) are also essential elements of recovery.

Anders (2003) analysed findings from several studies suggesting that people with mental illness in some developing countries have better outcomes than those in developed countries. She identified key elements that could be responsible for this difference regarding the integration and recovery from psychosis, suggesting:

- a sense of respect for and valuing of the person, rather than stigmatisation and exclusion;
- a strong community response that includes support (and mentoring by people who have had similar experiences);
- inclusion in community activities, and a renewal of belonging within the community through ritual;
- together with hope, a meaning-making process that fosters the person's sense of self and purpose.

However this is not the case in all developing nations, as in some present-day African countries, people with mental illness are often feared or devalued as it is believed that they are afflicted with witchcraft (Sayce, 2000).

Recovery is not a sudden transformation or a linear process, but a slow, evolving process that requires substantial commitment and involves positive growth as well as setbacks (Hensley, 2002; Jenkins & Carpenter-Song, 2005; Ochocka et al., 2005; Onken et al., 2007; Ridgway, 2001). Recovering is a process of improvement from the impairment of the symptoms of the illness, or a mastery over the illness, a reduction of the disabling effect of the impairment, and overcoming stigma (Onken et al., 2007). Chovil (2005) sees recovery as an adaptation process – both to one’s illness and then to the world around. Walsh (1996) describes recovery as an internal process in which psychiatric rehabilitation provides an external structure, with its emphasis on functioning rather than on illness and limitations, supported by values of involvement, choice, support and growth potential.

### **2.2.1 The importance of social connection and supportive environments**

Being part of a community provides all human beings with personal identity, common purpose with others, friendship, support, and a sense of belonging (Sayce, 2000).

Improved outcomes and recovery are linked to social connection and supportive relationships (Anthony, Rogers, & Farkas 2003; Onken et al., 2007; Wong, Matejkowski & Lee, 2009). Brown, Shephard, Merkle, Wituk, and Meissen (2008), investigating the link between being a member of a consumer-run organisation and recovery, found that a “socially supportive participation experience” (social connections or friendships that include elements of mutuality, support, intimacy and sharing) was essential in recovery. According to service-users, recovery is a social process whereby hope is instilled through supportive relationships providing inspiration, education and support, giving a message that living a productive and satisfying life is possible (Mancini et al., 2005).

The literature is filled with references to many people with mental illness who live without adequate social support, which increases their social isolation and feelings of loneliness (Kilbourne, McCarthy, Post, Welsh, & Blow, 2007; McCorkle, Rogers, Dunn, Lyass & Wan,

2008). In a review of the literature, Kilbourne et al. (2007) concluded that lack of social support was associated with reduced quality of life and increased disability. In another review, Wong et al. (2009) reached the conclusion that people with mental illness were dissatisfied with their relationships, and confirmed in their study that stigma constituted a significant factor. Buck and Alexander (2006) demonstrated that people with mental illness can form relationships, and desire to do so.

Vandevooren, Miller, & O'Reilly's (2007) review of the literature on mental health (as well as physical health outcomes) concludes that an emotionally supportive relationship is important to a person's well-being. Support and encouragement from family, friends, peers and mental health practitioners is a crucial determinant of recovery (Ridgway, 2001; Walsh, 1996). The self develops in relationship to others, and there is a mutual influence of response to and experience of life (Estroff as cited in Spaniol & Gagne, 1997).

Interactions with others can influence the individual's capacity to draw on their intrinsic motivation, which underpins personal aspects of recovery (Onken et al., 2007). Participation in support groups (with the element of universality, sharing similar experiences and feelings, engaging in similar struggles and feeling understood) is an important part of recovery (Walsh, 1996). In a review of the literature, Brown et al. (2008) concluded that in the process of sharing with others, a validation and normalisation of the experience of having a mental illness takes place. This reduces the individual's sense of isolation, providing social roles and increasing feelings of belonging and participation in community life.

Meaningful activities with others in different roles provide a connection to the social world, and increase a person's sense of worth and personal fulfilment (Herman et al., 2005; Smith, 2000). Developing the social competency to live and interact with others (generally referred to as social skills) is a significant facet of recovery, together with the individual's belief that he or she can make important and real contributions, and participate fully in his or her community (Onken et al., 2007; Ridgway, 2001). An important outcome for service-users of self-help groups is the gaining of more friends (Mowbray & Tan as cited in Brown et al., 2008). The value of friendship was demonstrated in the study of Davidson, Stayner, Nickou, Styron, Rowe, and Chinman (2001), who investigated a supported socialisation programme, looking at friendship, reciprocity

and hopefulness as important elements of recovery process. They concluded that friendship offers not only companionship, comfort and a sense of belonging, but also positive psychological gains.

In a study that assessed 32 people with mental illness, social support was found to be vital to the quality of life of people with schizophrenia (Eack, Newhill, Anderson & Rotondi, 2007). Satisfaction with social relationships is based on the reciprocity of relationships – giving and contributing to the exchange – rather than individuals playing a recipient role only. This in turn leads to increased self-worth and self-respect (Davidson, et al., 2001; Wong et al., 2009). Pierce (2004) cited peer support as being critical to developing confidence and as a connection to the wider community. Bond et al. (as cited in Bond et al., 2004) suggested that integration into community life increases a person's confidence and autonomy, and instils hope.

In their review of the literature, McCorkle et al. (2008) concluded that the psychological benefits of social support for people with mental illness include improved self-esteem, sense of autonomy, and enhanced quality of life. Outcomes for members participating in an intentional friendship programme were improved self-esteem, increased self-worth and confidence, with reports of members being more outgoing, sociable and socially active (McCorkle et al., 2008). In a review of the literature on the relationship between social support and outcomes, Corrigan and Phelan (2004) concluded that improved quality of life seems to be a consequence of larger or more satisfactory social support networks, and their study findings confirmed that recovery – as a process that includes goal orientation and hope – is associated with social support. They also found that satisfaction with social networks increases with the degree of connectedness experienced.

A supportive community – with a culture of inclusion, hope, genuine connection, caring, empowerment (including choice and self-determination), safety, dignity, respect and trust – facilitates recovery, and could reduce the detrimental effects of stigma and the experience of living with a mental illness (Jacobson, 2001; Mead & Copeland, 2000; Walsh, 1996). Herman et al. (2005), in their investigation of a clubhouse community, identified elements of positive interactions that lead to feelings of connection, including emotional investment, valuable

interactions and joint participation in meaningful activities – all of which provide common bonds and affirmation, and enhance feelings of mutuality, belonging, acceptance and approval.

Further evidence of these interpersonal effects was provided by the studies of Brown et al. (2008) and Sells et al. (2004). In turn, the interpersonal effects produce feelings of usefulness and a sense of importance. In their review of the literature, Herman et al. (2005) concluded that supportive environments are expected to impact positively on the quality of life of people with mental illness, as they play a significant role in enhancing psychological well-being, self-efficacy and feelings of hope. Their findings in the above-mentioned study supported this conclusion. In their review of the literature, Mancini et al. (2005) concluded that supportive environments contribute to the formation of a positive sense of self, during which the individual gains self-worth, new capacities, confidence and meaning. Access to a safe space with a familial atmosphere and positive activities not only provides social support, but also enhances self-esteem (Whitely, Harris, & Anglin, 2008).

The narratives of people living with schizophrenia in the study of Sells et al. (2004) reiterate the role of social factors – providing a sense of affiliation – and the value of opportunities for people to define themselves as worthwhile and effective. Kahng & Mowbray (2005) found that participants in their study reported higher self-esteem the more they engaged in positive social roles.

### **2.2.2 The importance of the development of a positive sense of self**

Developing a sense of identity, separate from the impairment-induced disability caused by the illness and the associated stigma – both of which the person is obliged to endure – is critical for progress in recovering from mental illness (Davidson et al., 2003; Deegan as cited in Sells et al., 2004).

Davidson et al. (2003) stated that feeling worthwhile as a person – a feeling induced by socially supportive reciprocal relationships in which one is valued and cared about, as well as being a contributor to the relationship – is vital for developing hope and building sufficient confidence to take the necessary risks in the course of recovery. Recovery is seen as a complex identity transformation in which the development of a positive sense of self is critical and the illness is

integrated as a part of the self, but does not define the entire person (Jenkins & Carpenter-Song, 2005; Mancini et al., 2005; Ridgway, 2001). Subjective feelings of life satisfaction are linked to positive appraisals of the self, induced by experiences in which one's self-esteem is reinforced. In a review of the literature, Sells et al. (2004) concluded that a sense of agency in the development of a positive self may contribute to better outcomes for people with schizophrenia.

Empowerment – a sense of internal control and personal power – requires taking responsibility for self, and allowing the illness to become less dominant; it is an essential ingredient of the recovery process. Self-acceptance aids empowerment and the greatest barrier to acceptance are feelings of shame about parts of self that were felt to be unacceptable to the individuals themselves (internalised stigma) or to others (Spaniol & Gagne, 1997). Similar to hope – as well as building on hope – acceptance requires others to be accepting of people with mental illness. In their connecting with others, people with mental illness can in turn be more accepting of themselves (Spaniol & Gagne, 1997). Acceptance involves affirming one's strengths and recognising deficits; and dealing with the loss of dreams, the former self, and being left behind by peers (Ridgway, 2001; Spaniol & Gagne, 1997).

Recognising and building on one's strengths is seen as essential to rebuilding self-image and improving self-esteem and self-confidence, and to overcoming doubt and gaining a sense of dignity (Ridgway, 2001; Smith, 2000). A sense of agency, together with self-determination and the awareness that change is possible with the envisioning of a better future (which involves a sense of personal capacity, and the ability to make use of opportunities) are part of the personal elements of the journey of recovery (Onken et al., 2007).

Mead (as cited in Vandervoort, 1999), an objects relations theorist, links the development of a positive personal identity to affirmative social relationships, which give us meaning in life. The close links established in the literature between a positive sense of self and supportive social relationships are central to the recovery process, and important in the rehabilitation of people who have mental illness.

### **2.3 Psychosocial Rehabilitation (PSR)**

An underlying assumption of PSR is that people with psychiatric disabilities have the same hopes, desires and dreams as any other individual in society – to be part of the community, to feel socially connected and to have valued social roles, for instance work (McReynolds, 2002). Medication only treats the symptoms; it cannot teach people with mental illness how to live successfully and productively in a community.

PSR consists of a variety of interventions or services that encompass teaching skills and provide supports, thus enabling people with mental illness to reach for optimal independent psychosocial functioning, with minimal impairment, in meaningful life areas of community participation that are important to them – including work, education, socialisation, friendship, family and recreation, and other roles they might choose to fulfil (Anthony, Kennard, O'Brien & Forbes, 1986; Lucca & Allen, 2001; Sheets, 1993; Stromwell & Hurdle, 2003). An important emphasis in PSR is the assessment and development of a person's skills, as opposed to diagnosing and treating symptoms (Anthony et al., 1986; McReynolds, 2002). The important aspect is to identify the skills deficit – whether a lack of social or coping skills, of symptom management or self-care – that prevents the person from effective functioning (McReynolds, 2002).

PSR acknowledges the importance of the individual's social role, as well as the fact that the initial breakdown with a mental illness has interrupted the development of the individual's role in society. Recovery therefore needs to be focused on re-establishing and developing one's social role, along with other capacity-building interventions (Schiff, 2004). Positive reinforcement is an important element of PSR. It supports people in their skills-building process to meet the performance expectations of the roles they choose to develop in their particular life settings (Sheets, 1993).

Rehabilitation aims to reduce the impact of disability and attain social integration for people with mental illness (Jacobs, Davidson, Steiner & Hoge, 2002). Programmes such as the clubhouse model, psychosocial groups, supported housing, and consumer advocacy groups are designed to assist people with mental illness to improve functioning, cultivate valued relationships, engage in vocational pursuits and adapt effectively in the community (Stromwell & Hurdle, 2003). The

focus is on the individual's aspirations, abilities and strengths, as opposed to focusing on the patient role and the symptoms (Craig, 2006; Pilling, 1991; Sheets, 1993; Stromwell & Hurdle, 2003).

According to Craig (2006), services' success in facilitating recovery lies in the culture of empowerment, healing and hope as well as the provision of interventions that reduce the impact of the disability and enhance quality of life. A combination of client choice (with an emphasis on collaboration) and being treated with respect and dignity achieves better outcomes (Craig, 2006; Sheets, 1993). One of the most important aims of rehabilitation services is to rekindle hope of recovery (Anthony et al., 1986; Craig, 2006; Sheets, 1993; Stromwell & Hurdle, 2003). In PSR programmes there is an emphasis on providing safe spaces, where meaningful interactions with others may contribute to skills development and social competence, increasing social confidence and reducing anxiety (McReynolds, 2002; Starkey & Flannery, 1997). Opportunities for valued shared social experiences enhance social competency and adaptation (Pilling, 1991). Research suggests that program members value the socialisation aspect of programmes, especially recreation activities (Lucca & Allen, 2001).

Another hallmark of PSR programmes is the focus on a sense of mastery through an increase in coping and functional skills, as well as on encouraging participation and taking responsibility for internally motivating goals (Starkey & Flannery, 1997). The aim is to develop a positive sense of self in line with recovery principles. PSR encompasses the principles of empowerment, choice, ability and healing (Anthony et al., 2003; Sheets, 1993; Stromwell & Hurdle, 2003).

Rehabilitation requires the service-user to be an active participant in his or her own recovery process, which increases self-esteem and hope (Sheets, 1993).

The mission of PSR is "is to assist persons with long-term psychiatric disabilities to increase their functioning so they are successful and satisfied in the environments of their choice with the least amount of ongoing professional assistance" (Anthony et al., as cited in McReynolds, 2002, p. 63). The aim of PSR is that the person with mental illness achieves maximum independent functioning, satisfying social functioning and a subjective quality of life that includes a personal sense of well-being (Corring, 2002; Glynn, 2003). PSR is an empowerment model, which seeks

to assist clients in making adjustments that will lead to improved life satisfaction and adjustment, and increase their sense of agency.

### **2.3.1 The clubhouse model**

One model of psychosocial rehabilitation is the Fountain House clubhouse programme which provides social, educational and vocational opportunities for people with mental illness. The cornerstone of the model is the belief that work has profound meaning in one's life, as it provides one with a role which serves to define one's identity (Beard, Propst, & Malamud, 1982).

According to Vorspan (1992), discovering your capabilities and strengths through work or meaningful activities enhances your self-esteem, which assists in the development of personal and work relationships

Over 350 clubhouses operate around the world. Service-users of clubhouses are called 'members' in order to create a new social role for them, rather than the role of 'patient'. Clubhouses, as intentional communities, provide social connections and foster a sense of belonging, offering participants affiliation, fellowship, support, affection, and shared emotional experiences which may aid in their recovery (Herman et al., 2005). Guiding principles of the clubhouse model include:

- the clubhouse belongs to its members;
- daily attendance is encouraged, as it distributes the workload; and
- members feel wanted and needed for their contribution to the workday (Beard et al., 1982).

Members and staff share real work that is vital in terms of the functioning of the clubhouse, and they work alongside each other, achieving goals for the day (Vorspan, 1992). The informal work environment teaches appropriate behaviour at a place of work, and also allows for recreation and other group activities. Various work units are responsible for specific tasks needing to be done, and members volunteer (an important aspect of providing choice) for the units in which they choose to contribute their skills. In the process they learn new skills or improve existing skills. The aims of the Fountain House programmes are to increase hope, improve work habits and enhance social skills, while providing a sense of belonging through being valued and needed (Beard et al., 1982; Vorspan, 1992). Cornerstones of the clubhouse culture according to

participants in the study of Norman (2006) included meaningful relationships, meaningful work activities and a supportive environment. The work-ordered day of the clubhouse seemed to address social isolation, loss of status, lack of sense of belonging and problems find meaningful ways to occupy time. It provides a framework from which relationships can develop.

#### **2.4 Positive outcomes of PSR programmes and service-users' experience**

Community integration seems to be enhanced by service-users developing a positive sense of self, becoming actively involved in managing their own lives, living with the illness and partaking in community and socialisation activities of choice (Stromwell & Hurdle, 2003). This also provides a framework for measuring outcomes. Enhancing service-users' interpersonal skills, independence, symptom management and ability to secure work is recognised as a constructive outcome for people with mental illness (McReynolds, 2002). The study of Lecomte, Wallace, Perreault and Caron (2005) reiterates the concordance between service-users' goals and the service provided. Frequently mentioned goals in this study were the improvement of economic circumstances, relationships, physical and mental health, and cognitive capacity.

Self-help groups for people with psychiatric disabilities have shown that people gain hope through participating in the group culture of mutual support, respect and co-operation. This leads to improvement in interpersonal skill as well as an increase in numbers of friends (Murphy as cited in Luk & Shek, 2008). Davis (as cited in Pilling, 1991) elicited service-users views on day centres through individual interviews, and found that day centre service-users valued having a place to go to, having something to do as well as meeting people and developing social relationships.

In the study of Vandervooren et al. (2007), important positive changes were measured in terms of symptom reduction, increased social skills, improved judgement and insight, increased attention span and better money management. These outcomes imply that supported housing (together with rehabilitation) prepares people for more independent living.

Berry & Poorhady (2007) provided preliminary evidence to suggest the rehabilitation programme they were assessing was meeting its objectives of skills development and community integration. They did feel that a limitation in their study was the possibility that the perceptions

of the staff who administered the measures could have biased the study outcomes. In the study of Doğan, Doğan, Tel, Çoker, Polatöz, and Doğan (2004), improvement in the areas of quality of life, family and social relations, communication skills and social interaction – by way of improvement in social adaptation and more appropriate role behaviour – demonstrated that a psychosocial support and education rehabilitation programme has a positive effect on people with schizophrenia. These findings seem to suggest that satisfying and meaningful activities (as opposed to employment only) can contribute to subjective quality of life. In evaluating preferences for rehabilitation outcomes, Cradock, Young & Forquer (2002) found that service-users and their families valued social support highly as an outcome, and that neither group valued outcomes related to employment.

A study by Luk and Shek (2008) investigated the subjective experiences of personal change among service-users participating in a holistic rehabilitation programme in China. The findings reported the following changes on a personal level:

- increase in positive feelings (for instance, happiness and cheerfulness);
- development of positive thinking (optimism); and
- improved self-esteem (reduced feelings of inferiority).

The theme of increased self-esteem and sense of self worth was closely linked with being accepted, respected, valued by others, having friends and contributing in the group. The findings reported the following changes in the social dimension:

- improvement in interpersonal skills (for instance, openness, expressiveness and trust);
- an increase in use of social networks; and
- access to positive learning opportunities.

Important in this process was the theme of universality – shared understanding and identification with each other – which reduced feelings of isolation and alienation. There were also changes in the spiritual dimension: the development of meaning and purpose through a process of acceptance.

Participants in the clubhouse study of Herman et al. (2005) felt that the programme promoted a sense of community. Important elements were supporting recovery; promoting hope; and providing affirmation, coping skills, psycho-education and the opportunity to connect to people and learn social skills – in addition to being a safe space. This is in line with the programme goals of providing a support system and engendering a sense of belonging, which reduces isolation.

In an investigation of quality of life from the perspective of people with mental illness, the following were described as critical and contributing to self-esteem:

- good support network (people to listen, to understand, to validate and to trust);
- engagement with peers in meaningful activities in “a place where you belong” and feel safe;
- a sense of being included, wanted and accepted in the community (Corring, 2002).

Positive attitude, pride, a sense of humour and taking responsibility for oneself were personal aspects seen as integral to quality of life (Corring, 2002). These findings are in line with the recovery paradigm and PSR principles of integration into the community and rebuilding a positive sense of self.

Using various questionnaire measurements, including conventional measures of life satisfaction and absence of psychiatric symptoms, as well as measurements of dimensions of social support and relationship characteristics and measures for self-esteem, feelings of control, feelings of joy and enthusiasm, Bracke (2001) explored the link between participating in a psychosocial rehabilitation programs and quality of life. Substantial and statistically significant changes in well-being, an increase in self-esteem, increased feelings of joy and increased internal locus of control were concluded to be outcomes. A direct link was established between self-esteem and social interactions (Bracke, 2001) – further evidence for the importance of supportive peer relationships.

The wide variety of possible outcomes is very usefully summarised in the table from Hutchinson, Gagne, Bowers, Russinova, Skrinar, & Anthony, W.A. (2006), who provided a framework of possible functional health outcomes for people with severe mental illness. This is included in appendix A (p. 93).

## 2.5 Measuring outcomes in the mental health field

Measuring outcomes in mental health is challenging; mental illness is a subjective experience, and outcome measures can be difficult to define (Schofield, 2006). People with mental illness have their own goals, needs and preferred outcomes, which are often different to those of family members and service-providers (Kravetz, Faust & Dasberg, 2002; Schofield, 2006; Speer, 1998). Evidence-based practices (which have become increasingly important) need to take into consideration the recovery paradigm, and the question of what constitutes 'evidence' becomes important (Anthony et al., 2003; Davison et al., 2009). Many PSR programmes do not lend themselves to the rigour required by 'gold standard' randomised control trials for producing evidence; but they could be vital in expanding our knowledge regarding recovery and what constitutes desirable and meaningful outcomes for people with mental illness (Hutchinson & Razzano, 2005).

Positive outcomes do not necessarily mean an eradication of symptoms; 'improvement' may mean different things to different people. Many people are able to live satisfying lives despite continuous auditory hallucinations (Hearing Voices Network, 2009). Measures using number of relapses and hospitalisations are not adequate, and measures that look at degree of independent living, or satisfaction within the life areas of living, learning, working and socialisation have been suggested as appropriate outcomes (Anthony et al., 1986). Anthony et al. (1986) suggested that an important outcome of psychiatric rehabilitation is client behavioural change. Measures of behavioural change ask whether a person can do anything differently as a result of participating in a programme. What skills (for instance, the ability to engage in conversation and connect to people socially) have they learned or regained, and what activities are they now performing or participating in? Dominant cultural views may affect how others view outcomes, especially in relation to competence in respect of fulfilling instrumental roles, such as 'worker', 'student', etc. (Glynn, 2003). Sheets (1993) stated that 'outcome' is defined as success and satisfaction of functioning in specific life roles, which would include the presence of skills needed to perform according to the expectations of these roles, as well as the self-esteem related to this role.

The importance of quality of life as a rehabilitation outcome has come to the fore recently, and researchers are asking what impact services have on subjective well-being and life satisfaction

(Speer, 1998; Wu, Mak, & Wan et al., 2007). Simmons (as cited in Corring, 2002) argued that subjective quality of life can only be accessed through self-reporting measures (as cited in Corring, 2002). In a review of the literature, Bracke (2001) reported that subjective well-being and satisfaction with life relates to feelings of empowerment, sense of control, mastery, autonomy, self-efficacy, perceived competence, feelings of joy and enthusiasm, self-acceptance, self-worth, and good self-esteem, as well as supportive relationships. Subjective well-being is more than satisfaction in life areas, or the simple absence of symptoms. Objective quality of life scales include social behaviour and recreational activities, independent living skills, and employment (Górna, Jaracz, Rybakowski, & Rybakowski, 2008).

The absence of self-reported data has been identified as a limitation in several studies, and the voice of the service-users and their perspectives on their own functionality have been neglected (Berry & Poorhady, 2007). Self-reporting on areas such as quality of life requires a degree of insight, self-awareness, and introspection; and a cognizance of quality of life issues, any of which may not be present. Another issue is the importance of including service-users' opinions concerning what constitutes preferred outcomes, because of the lack of agreement between various stakeholders (Berry & Poorhady, 2007; Speer, 1998).

## **2.6 Conclusion**

Recovering from mental illness is a non-linear process of overcoming psychosocial dysfunction. Besides symptom management, it means moving from psychological damage (which may have severely affected areas of identity, self-esteem, self-worth, confidence, pride, feelings of mastery, sense of control, and sense of meaning and purpose) to rebuilding a positive sense of self. It also involves overcoming the disabilities that affect daily living, and hamper the functional, coping, social and work skills that underlie the individual's engagement in the world, which constitute the bedrock upon which a sense of valued self is built.

Psychosocial dysfunction also affects the ability to access and participate in valued meaningful activities and supportive relationships. These effects are compounded by stigma, which leads to exclusion and isolation. Loss of relationships and valued social roles may be the most devastating impact of mental illness, as it destroys a person's sense of belonging and self-esteem;

and it is partly due to impairment of the ability to relate to others, difficulty in maintaining social relationships, and loss of social skills, as well as the stigmatisation of mental illness.

Evidence is accumulating that opportunities for participation in valued, meaningful activities (not necessarily work) within a social context may be vital to building a positive sense of self in the recovery process. Meaningful activities may provide a person with feelings of usefulness, and constitute a bridge to the social world. Social connection and supportive relationships have been associated with various health benefits and are essential to a person's well-being, while disconnection and isolation are linked with increased disability and reduced quality of life. For persons who only know exclusion and marginalisation, mutually satisfying relationships are in themselves a preferred outcome. Research indicates that most people with mental illness have inadequate social networks; and this lack of social support adds to the despair of living with a mental illness.

A positive social connection fosters trust and a sense of belonging; and instils hope, which may be a key component to the recovery process, as it counters helplessness. Being included (and thereby feeling that one is a worthwhile person), being accepted, respected, valued and cared about by others enhances self-esteem, as well as other aspects necessary to the building of a positive sense of self. Such an identity transformation involves a process of recovering from the losses caused by psychological damage and the diminution of skills necessary for engagement in the world, as well as demanding a separation from the illness and the accompanying stigma. Personal aspects of recovery appear to need a social context which makes supportive communities such as those found within the PSR programmes essential, especially since stigma remains a problem.

PSR programmes provide safe spaces for people with mental illness, creating opportunities for meaningful interaction with others. This leads to valued shared social and emotional experiences, which enhance the service-user's confidence and self-esteem while building social skills.

Universality, and sharing with an understanding other, serve to normalise living with a mental illness. Development of a positive sense is initiated through increasing a person's coping and functional skills (starting with the person's strengths and skills), thereby increasing a sense of mastery. PSR programmes value the social context by providing hope of possible recovery, in

contrast to many individuals' first contact with the mental health field. Research on PSR programme outcomes provides support for the importance of personal aspects of recovery as well as the value of socially supportive relationships, and often demonstrates that they are intertwined.

Various debates exist concerning the outcomes of programmes; particularly regarding what constitutes outcomes, and how to best measure them in order to provide evidence-based interventions. Subjective quality of life appears to be closely linked to whether we have a meaningful existence that is delineated by sense of self and place in the world. The impact PSR programmes have on quality of life needs to take into consideration the facets of a positive sense of self, as well as valued socialisation experiences. Recovery can be defined as a significant, positive change in a person's life, which is valued by that person.

University Of Cape Town

## **CHAPTER 3: METHODOLOGY AND RESEARCH DESIGN**

### **3.1 Research paradigm: A qualitative and participatory approach**

The qualitative method is a useful way of understanding and describing the issues under investigation from the participants' viewpoint. The value of the qualitative participatory research approaches lies in their richness and how embedded they are in a real context. Emphasis on lived experiences empowers people, through the process of using their own knowledge to construct understanding (Miles & Huberman, 1994). From the point of view of the participants, this enhances the credibility and trustworthiness of such research.

It also equalises the relationships between professionals and service-users and serves to align the research process with empowerment principles, as the power differential that usually exists between researcher and participants amplifies the powerlessness of already marginalised groups. A concern around the issues of power was central to this research. A relationship of trust already existed between the researcher and many of the participants, as a result of the researcher's previous position as programme co-ordinator of Fountain House. This added to the participants' acceptance of and sense of comfort with the research process. Accessing this vulnerable population group as part of their own programme's activities made this research seem non-intrusive, and presented the research as a normal activity.

This is an explorative study that seeks to describe the subjective experiences of participants in the Cape Mental Health Society PSR programme. In this case study a comparison will be drawn between the programme aims and outcomes as experienced by participants in the programme.

### **3.2 Evaluation of programme outcomes: Participant views**

#### **3.2.1 Most significant change technique (MSC)**

For the purpose of this study the most significant change technique (MSC) was an appropriate tool, as I was interested in the effect of psychosocial rehabilitation and the difference it made in people's lives. In line with the intervention's participatory ethos the researcher wanted to give voice to the service-users, primarily with regard to the aspects they deemed to be most significant.

The core of MSC is an open question, which included the following elements:

- “Since you became ill / Since you have participated in the programme...” – refers to a specific time period;
- “...what do you think...” – asks for the opinion of the participant;
- “...is the most significant...” – asks the participant to be selective, and report on one thing;
- “...change...” – asks for something that is different, that did not stay the same;
- “...in the quality of your life...” – though this is a broad area, it also establish boundaries.

The MSC technique is applicable to the monitoring and evaluation processes within programmes involving participants in a participatory manner (Davies & Dart, 2005). The usefulness of MSC is that instead of measuring whether activities have achieved objectives via staff outputs, data is generated on the impact and outcomes for individual participants of the programme (Davies & Dart, 2005). A rich picture of actual change can be provided, as opposed to the capturing of numbers.

The process involves collecting stories of change. Once the stories are collected, the comprehensive implementation of MSC involves in-depth discussions between various stakeholders about the value of these changes. Then a choice is made about which story represents the most significant change, with a discussion of the selection criteria, making the process collaborative throughout the hierarchy within organisations (Davies & Dart, 2005). However, for the purpose of this study the selection process of the most significant story within all significant change stories that were collected was not included, as the focus was on all outcomes important to participants and how they compared with programme aims.

For the purpose of data collection, the Stage 1 focus groups were used to identify broad themes – that will be called domains from here on – of changes in people’s lives. Stage 2 involved the collection of further personal stories during the focus groups within the wider PSR community (Fountain House, Rainbow groups and Kimber House). These domains differ from performance indicators as they are not precisely defined, but rather are open to individual interpretation. The domains were not included in framing the focus question during the data collection process, and the participants of Stage 2 focus groups were allowed to respond in any domain category.

### **3.2.2 Data collection methods: Focus Groups, Stage 1**

Participatory research requires that service-users participate actively in all stages of the research, from the initial conceptualisation of the research to planning, data collection and analysis (Rogers & Palmer-Erbs, 1994). The preliminary data collection method used during Stage 1 of this research was focus group discussion, with the aim of generating themes in respect of outcomes from participation in the PSR programme. The aim of the Stage 1 focus groups was the co-constructing of meaning with regard to what constitutes outcomes from a service-user perspective, thus utilising participants as insider-researchers to set up a map of the terrain to be explored. This is in line with the proposal of Anthony et al. (2003) that outcomes should be defined according to those that service-users believe to be most critical within the recovery paradigm.

The stage 1 focus groups were drawn from CCAB, where members are very knowledgeable concerning issues relating to mental health service-users, and have represented service-users regularly in various forums. The stage 1 focus groups featured free-flowing discussions, with group members asking each other questions in order to elaborate on the themes. The service-users for the Stage 1 focus groups were drawn from a higher-functioning group who could articulate their ideas, as opposed to more disabled service-users who have greater cognitive difficulties and are more severely affected by their illness, such as those with ongoing positive and negative symptoms. This bias is cause for criticism in many studies. However, in this study the real experience of those service-users that generally access the programme was also tapped into, as participants from the Stage 2 focus groups presented with various levels of functioning and dysfunction. Information from two layers of the programme service-users therefore provided internal validation of similar results.

The preliminary identification of outcomes through the data analysis of the Stage 1 focus groups was verified by the participants in those groups. This opportunity for checking understanding and interpretation of findings is an important aspect of participatory research (Rogers & Palmer-Erbs, 1994), and provided confidence that the results of the Stage 2 groups could be analysed in the same manner. The decision to have preliminary identification of domains was made to inform the data analysis, rather than to structure the group process of Stage 2, which we wanted to be as

open-ended as possible. This sharing of power and control over the research process is inherent in authentic participatory research, and involves participants in more meaningful and influential roles (Rogers & Palmer-Erbs, 1994).

Because of the varied possible outcomes identified during the Stage 1 analysis, together with awareness of the danger inherent in leading questions, and informed by the literature, in which ‘recovery’ constitutes a change, the decision to adopt the most significant change technique was obvious. As part of the Stage 1 process, the focus question “What has been the most significant change in your quality of life since you have accessed PSR?” was tested on the participants, who felt it to be a workable technique.

In addition, Stage 1 focus groups served as a platform for discussing methodology and concerns pertaining to the research process in general; but also, more specifically, regarding participants and issues surrounding mental illness (for example, disclosure of demographic information, especially regarding diagnosis). Mindful of these issues, we could approach the Stage 2 groups armed with increased sensitivity and awareness.

The strength of using focus groups is that they foster the development of a rich understanding of participants’ experiences and beliefs about what constitutes preferred outcomes, improved quality of life or significant positive change (Morgan, 1998). This is in line with the suggestion of Anthony et al. (2003) that the use of qualitative methods, which focus on the perceptions and experiences of the participants in the change process, can assist in defining the recovery process. They play a complementary role to quantitative measures that allow for causative interpretation of the factors that are responsible for the change and improvement.

The common ground found between the focus group participants (all having a mental illness and all having participated in the PSR programme) allowed the pooling of a wealth of knowledge, experience and expertise that could be used to guide the study from a service-user perspective. This is in contrast to the situation in which a researcher comes in with preconceived ideas and poses as an expert; rather, participants worked in collaboration with the researcher, instead of being subjects of the process (Herman et al., 2005; Morgan, 1998; Rogers & Palmer-Erbs, 1994).

The benefit of the sharing of information and ideas among group participants is inherent to the group context. Sharing increases universality, highlights common ground and experiences and, at the same time, gives hope for the possibility of change. A respectful research process provides participants with an opportunity to tell their story, engendering them with a sense of being listened to (Morgan, 1998). Several studies in the mental health field have used focus groups as a means to access the voice of the service-users, and have proved to be a useful source of information (Koppelman & Bourjolly, 2001; Onken & Slaten, 2000; Tanenbaum, 2008).

Due to financial (Stage 1 participants were refunded their transport costs) and time constraints, the data collection and analysis for Stage 2 was conducted without involving Stage 1 participants, though ideally they would have participated throughout. However, the continued use of focus groups as a data collection method allowed Stage 2 participants a meaningful role as well, which demonstrates the study's deep respect for experience-based knowledge.

### **3.2.3 Data collection methods: Focus Groups, Stage 2**

In the second stage of the data collection, focus groups were run in the wider community (Fountain House, Rainbow groups and Kimber House). When the focus groups were applied to the rest of the psychosocial programmes, less interactive discussion took place; however, participants did contribute their personal stories. The interactions within these groups produce 'thick data', as listening to others' verbalised experiences stimulates participants' memories of their own changes. The aim was to track each participant's personal journey and perceived history of improvement in their lives, their relationship with themselves and others and the impact of PSR on their experience and quality of life. Five Stage 2 focus groups took place, ranging in number from six to thirteen participants. Two groups were held at Fountain House with different participants, about one week apart and on different days of the week. This was in order to get a broader and fuller representation of participants as different Fountain House members attend on different days. Two focus groups were held with two different Rainbow Foundation groups, and one focus group was held with Kimber House residents.

### **3.3 Data collection**

#### **3.3.2 Sample**

##### **3.3.2.1 Participants**

A total of forty-four service-users of the Cape Mental Health Society PSR programme participated in the study. During stage 1, four focus groups, involving between four and six members from CCAB (total seven participants) were conducted (these numbers were not included in the sample accounting). A Total of thirty-seven service-users participated in the focus groups in the wider PSR community as follows: two groups at Fountain House, with six and thirteen participants respectively; two Rainbow groups were accessed in their respective communities; and one group at Kimber House with four of the eleven residents participated in the research. Eight people participated in the Athlone Rainbow group and six people participated in the Kraaifontein Rainbow group, both being disadvantaged communities. These suburbs form part of the historical Cape Flats, which is where people have been removed to during implementation of the (previous) apartheid government's Group Areas Act – a segregation policy.

A total of nineteen participants (51% of the sample of thirty-seven participants) suffered from Schizophrenia, seven suffered from Bipolar Mood Disorder, four from Major Depressive Disorder and three from Schizo-affective Disorder. Some participants refused to disclose their diagnosis, and others simply did not complete their forms. The Rainbow Foundation groups are situated in traditionally coloured communities and most of the members are coloured, which explains the high percentage (51%) of study participants drawn from this racial group. The majority of the participants were between the ages of 31 and 40 years (40%). 78% of the participants were single, 88% unemployed and 62% living with their families. 40% of the sample group had been part of the PSR programme for less than a year, but most of these attend Fountain House or Rainbow Foundation at least once a week, while 33% of the sample currently attend Fountain House every day. A table with all the demographic information of Stage 2 group participants is available in Appendix B (p. 94-97). No demographic information was collected for the Stage 1 (CCAB) focus groups, as the data from these participants was not used in the accounting process, but served a different purpose.

### **3.3.2.2 Recruitment of participants**

In line with the empowerment model, the sampling procedure was designed to afford choice to potential participants as to whether they wanted to be part of the research process or not. An advertisement was placed in the programme's newsletter, and staff of the programme made announcements at various meetings, handing out flyers advertising the research. Not a single participant came forward to express interest, which may be related to the negative symptom of avolition, or decreased risk-taking behaviour. After negotiation with the management of the programmes, it was decided that the researcher would use a slot usually taken by a regular life-skills group at Fountain House, and after explaining the research project, the researcher would invite participants. The researcher also attended the Rainbow Foundation group leaders' meeting, and together with them the researcher identified two groups suitable for participation. The group leaders reported back to their group members, who gave their permission for the researcher to use a regular group time slot to conduct the focus groups. With permission, the researcher visited Kimber House to ask directly if the residents would be interested, and set a date for the data collection.

### **3.3.3 Process**

At the Stage 2 focus groups, the researcher first introduced herself, explaining the research and the confidentiality aspects, and allowed time for questions. Participants were required to complete the demographic information sheet, after it was stressed that they were not obliged to disclose any information with which they felt uncomfortable. Recording started with the researcher asking participants to relate their personal story of most significant change – first, since being diagnosed (when they first fell ill) and, thereafter, since accessing PSR. On most occasions there was a natural flow between the two questions, as participants spontaneously began talking about how things had changed since accessing the group. Possibly this was due to the natural tendency to talk about positive rather than negative issues. Most participants were reluctant to engage directly in conversation about loss; however, enormous losses were implicit in the gains described since participating in the programme. Fifteen participants contributed extensively, and were rich in their descriptions of the most significant changes in terms of losses subsequent to having been diagnosed.

For various reasons, not all participants contributed to the data in terms of outcomes of the programme. Some did not speak into the microphone with the result that the recording was inaudible and could therefore not be transcribed. Other participants were known not to speak much (specifically, two individuals who had been members of the programme for 14 and 22 years respectively), but still seemed to enjoy being part of the groups, as they showed interest in the proceedings. It might have been better to engage with these members on an individual level. The Fountain House group was too large (13 participants) and some participants either lost interest or could no longer concentrate, and left the group before they had contributed. A total of eight participants did not contribute to the data, and are not included in the accounting for data analysis. The contributions of 29 participants addressed the research question.

Table 1

*Participants Contributing to Data*

	Fountain House Group 1	Fountain House Group 2	Athlone Group	Kraaifontein Group	Kimber House
Participants contributing to data	8	6	7	4	4
Participants not contributing to data	5	0	1	2	0
Total participants in the groups	13	6	8	6	4

### 3.4 Data Analysis

All focus groups were digitally recorded and transcribed. The transcripts of the interviews were analysed using first-level coding for summarising segments of data (Miles & Huberman, 1994). The method of analysis was a thematic analysis. The unit of analyses was monothematic ‘chunks’ of sentences and material unrelated to the research question were not coded (Miles & Huberman, 1994). Data reduction methods (as described in Miles and Huberman (1994)) were used to avoid a display of extended text that could tax the reader. Some text was paraphrased to demonstrate the commonality of themes, as well as to highlight what was essential to each person’s story.

### **3.4.1 Methods of collecting and analysing emerging data: Selecting domains and sorting themes**

The aim of the preliminary (pilot) focus groups was to generate ideas regarding change and outcomes due to participating in the PSR programmes, and to classify these according to overall themes or domains. The transcripts were analysed by sifting through the data and identifying phrases reflecting outcomes of PSR, recovery and improved quality of life. These phrases were highlighted with coloured pens, and a summary remark was noted in the margin. Both the researcher's familiarity with the field and the literature on recovery provided the researcher with the background from which to make these judgements. In addition, during Stage 1, the themes that emerged were taken back for validation at the next focus group.

The summarised themes were presented to the group participants on a data contact summary form, including the display of chunks of data in the form of direct quotes from the transcriptions, with similar themes clustered together (Miles & Huberman, 1994). This was used to identify gaps in, or deepen the understanding of, some themes and served as a provisional start list (Miles & Huberman, 1994) as well as a means of deciding overall descriptions of clustered themes, referred to as domains. Five descriptive domains were decided on, as follows: 'socialisation', 'personal', 'learning', 'living' and 'work', which (except for the domain of 'personal') correspond with the four life areas of PSR targeted in the programme under review. Social skills were classified as falling into the social domain, even though this subtheme could just as well have fitted into the learning or even personal domains.

Once this process was completed, and in order to serve as a guideline for data analyses for the focus groups in the wider PSR community, a two-way matrix display was designed, inserting direct quotes of perceived change together with the researcher's summary remarks, in order to identify and cluster subthemes together under the different domain headings (Miles & Huberman, 1994).

### **3.4.2 Method of analysing transcribed sessions**

Secondary analysis (Davies & Dart, 2005) involved the examination, classification and analysis of the content (or themes) across a set of significant change stories. A basic method of thematic

analysis was used, which was to search all the stories for different kinds of change, highlighting all changes and noting a summary remark in the margin for each segment of data highlighted. The data was then sorted and classified into categories that represented similar changes, and matched with the broad domains identified by the focus groups. This was done through ‘cutting’ from the original transcriptions and ‘pasting’ into columns under the domain headings, creating a display matrix. Stories were re-read to check and confirm change being referred to. For accounting purposes a table was created with a tick list to record which participants expressed a specific theme within each domain.

### **3.5 Comparison of participants’ evaluation and aims of the programme**

The themes identified by participants as significant change since accessing a PSR programme were compared with the aims and targeted outcomes cited in the description of the programme. A matrix was drawn up with the following columns: ‘programme aim’, ‘themes that emerged from this study corresponding to the aim’ and ‘percentage of the sample which responded in reference to that theme’. Themes that were important to participants, but that were not reflected in the programme aims, were highlighted.

### **3.6 Ethical aspects**

Participants were informed of the purpose of and procedure for the investigation at the start of each focus group. Voluntary participation was encouraged, which is in line with the PSR value of ‘choice’. Informed written consent was obtained from all participants, and they were assured that they could withdraw at any stage (Willig & Stainton-Rogers, 2007). See Appendix C.

The supportive nature of a group context may lead to quasi-therapeutic relationships (Willig & Stainton-Rogers, 2007), with perceived empathic listening and feelings of trust encouraging the person to reveal personal information, possibly leaving them feeling vulnerable and regretting what they had disclosed during the interview. However, in this study participants perceptibly felt relief after their disclosures, as well as affirmation that they were not alone in their suffering, as they noted similarities in the various stories. Participants were assured of the confidentiality of all research materials and the protection of their identity. Participants were informed that even though extracts from the interviews may be published, their anonymity was assured.

Permission for access to sample was received from the Director of CHMS, the Programme Coordinator of PSR and the CCAB Executive Committee, who represent service-users.

University Of Cape Town

## **CHAPTER 4: DATA ANALYSIS AND RESULTS.**

### **4.1 Data Analysis**

In order to understand what service-users have gained from participation in PSR programmes it is important to appreciate the progression of mental illness: from the initial breakdown – with immediate as well as long-term losses (usually the most significant change since diagnosis) – towards the process of recovery. In the analysis of the data the researcher first looked at the initial breakdown and the losses as described by participants; next, at what the recovery process meant for participants. The latter came to the fore in the CCAB focus group (Stage 1), as the focus question was more loosely defined, and more interactive discussion took place.

Further, the analysis looks at the most significant outcomes that participants have experienced as a result of participating in the programme. The researcher first discusses what emerged from the stage 1 focus group discussions, involving members of CCAB, and thereafter the most significant changes identified by the participants in the wider PSR community focus groups (Stage 2). Other themes and issues that emerged in each group context (Stage 1 and Stage 2) will also be discussed. As part of this analysis the researcher draws a comparison between the results from the two group contexts (Stage 1 and Stage 2), as well as a comparison of participants' responses according to gender and length of participation in programme (in Stage 2).

Finally the analysis looks at a comparison between the narratives of significant change and the aims and targeted outcomes of the CMHS PSR programme.

#### **4.1.1 Themes identified during the CCAB (Stage 1) focus groups**

It emerged from the Stage 1 focus group discussions that suffering from a mental illness involves major losses for the person diagnosed, particularly in the domain of social connection and interaction, as well as on a personal level. As one participant (Stage 1: Participant 1) said:

“Well, shortly after a breakdown – I am talking about my own experience – you feel raw. You are very sensitive and you are easily hurt. It is not easy to identify with people's intentions just after having had a breakdown – it's difficult to identify with people's intentions because your thought patterns are very scattered, and it's like you are reaching

up to grasp some type of meaning of what's going on around you. It's very difficult at first, but after time you will start to reach a certain level, with medication, that's 'normalised', and staying there is the task at hand then – once you reach that level, staying there becomes the task.”

In the social domain, various subthemes had a major impact: loss of connection to others, loss of people skills and social understanding, difficulty interacting, an inability to trust and converse with people (which could include a fear of people) – all leading to withdrawal from people, and isolation. Disconnection with family members was also mentioned. According to a participant (#1:7):

“I find it hard to trust people and to get their trust – to trust in me – and to bond and have a social life. I find that is very difficult to interact...”

In terms of personal losses, participants felt that cognitive ability is severely affected; especially in terms of awareness of generalities and difficulties related to thought, understanding and conceptualisation, which was compared to “starting from a blank canvas”. Loss of choice, confidence and dignity were also mentioned.

The loss of the ability and/or opportunity to work – an ability equated with normalcy – was identified as a major loss for people suffering from mental illness. As one participant (#1:2) stated:

“It's minimising what I've lost – you know, the ability to work and earn a living, and to live yourself out through your work or career.....”

Focus group members believed stigma to be a big issue, especially since many people with mental illness have a daily struggle with basic survival, and opportunities to move “back into society” are limited.

‘Recovery’ for Stage 1 focus group participants meant stability; and an increased awareness of one's own needs (whether social or personal), learning in incremental steps how to live with a mental illness, replacing what was lost. Some participants described this as introducing normality again and starting over, picking up the pieces and slowly building oneself up. All the focus group

participants considered it important to be functioning at the highest level possible and to be contributing to the full extent of one's capabilities. 'Wellness' is, according to a participant (#1:1):

“when you get to that situation where you are feeling on top of things, you are getting on well with your family, your relationships are good – those are all fantastic things and that can only help to then keep you well.”

According to focus group members, the PSR programmes played important roles in their recovery. One participant (#1:1) expressed the following:

“PSR catches you while you are falling... actually, just very plainly getting together and talking, it actually has quite a value because it's one-on-one, it's emotional, it's personal, it's not really dropping out of society – it's trying to add something to it.”

According to another participant (#1:4):

“Personally speaking... but for me, it's like – it's not something that I really climbed; it's like I got onto an escalator and it picked me up higher – those are the simplest words I can actually put it in, just to cut a long story short.”

One of the major themes identified as an outcome of participating in the programme during the Stage 1 focus groups was social connection and interaction. Group members felt the social aspect was an important facet of wellness, and speculated whether this was the most important aspect of PSR; because group members felt that the building of friendships represented a solid foundation for the individual in terms of recovery. This issue is reflected in the following comment by a participant (#1:1):

“I'm speaking from personal experience now, it [PSR] does help you, it gives you that confidence to come out and talk and just take that first step towards socialising, which was – for me – one of the biggest steps of recovery.”

It was acknowledged that socialisation is complex and involves many steps with which people with mental illness struggle and need to overcome in order to break through the isolation and loneliness, and to relate to and communicate with others. One participant (#1:1) reported:

“For me, PSR was the first step or so, on the ladder to recovery. Even when you start off with PSR you don’t want to participate and you see everybody – old members – opening up and confiding in one another, and then that helps you to relate to people, which is one of the steps crucial to the socialising.”

According to another participant (#1:7):

“For me, the big step was to trust somebody you can talk openly with about your illness, your hurt, your deep feelings – and for me, that was a breather”.

It was further discussed that the environment impacted on one’s ability to learn social skills; a supportive, nurturing space (that enhances one’s sense of belonging and induces feelings of being understood) is required in order to create the trust needed to enable one to express oneself and share openly.

Social skills that were identified were those of co-operation, and participation or working in the group context, for example (participant #1:2):

“PSR has taught us, actually, high-functioning, low-functioning, rich and poor, to have a decent meeting where people can get along as humanly as possible.”

The idea of universality was discussed as a supportive factor. According to a participant (#1:4):

“...where you actually try and normalise your experience after you’ve had that breakdown, by mixing with people who have a similar disability.”

Supportive factors that were valued by participants included the sharing of advice, motivation and encouraging of each other, and the sharing experiences. Integration with people from all walks of life was also mentioned as an important achievement gained from participating in the PSR programmes.

A second major theme of personal changes or improved outcomes identified during the focus group discussions included the following: self-esteem, confidence, insight (which includes self-knowledge), acceptance, an ability to trust, change in attitude, increase in motivation, hope, pride, focus, and realisation of own needs. One participant (#1:7) expressed:

“The encouragement part and the motivation and inspiration as well. Before, I couldn’t speak to anyone – I was very shy, I had no confidence at all – I had no dignity myself – I couldn’t look out or walk outside; and since I’m over here, basically, everything has changed for me. I see a different outlook on life.”

Further (participant #1:5):

“At Fountain House I also learned my strengths and my weaknesses, and it gives me insight – for the day, it makes me want to achieve my goal for the day, and then I know when I go home I have accomplished something.”

Changes in terms of learning were identified as a third theme during the Stage 1 focus group: besides social skills and self-knowledge (discussed above), these included learning about the illness, specialised skills such as computer skills, understanding banking accounts, and interviewing (as part of a panel) potential candidates to join the staff at the PSR Programme.

During the short discussion concerning the domain of living it was acknowledged that basic survival was often the challenge for most people with mental illness – where and how they live.

The discussion on the theme of work brought the following to light (participant #1:1):

“I was just looking at one of the other possible things – working – to do something which is quite normal. I think that's an area in which there's not really too much happening there – job opportunities and stuff – it’s difficult, so I think socialising takes the place of working. I don't know if that's such a good thing. I think it’s a good thing, because it’s energy that's getting used up, which is positive; but I think sometimes people want more.”

Further:

“Stigma is still a huge factor, especially in clients who are just making it and have absolutely no way of...[making it]... back into society at all... through employment, or just made to feel that they're part of society. You know, a lot of the poorer groups – it's terrible what's happening, you know.”

Permanent (or even part-time) employment appears to be difficult to access for people with mental illness, and did not really form part of the focus group discussion. However, being productive and useful – for instance, volunteering their services in the PSR programmes – has a beneficial effect, and seemed to replace work as a meaningful activity. According to a participant (#1:2):

“Pride is very important, to enjoy the work that you do as a member of the PSR society as a whole, and that pride of belonging to something.”

Because these major themes were identified, they were chosen as domains for data collection in the wider PSR groups, which included Fountain House, Rainbow groups and Kimber House, with regard to outcomes from participating in these programmes.

#### **4.1.2 Focus groups in the wider PSR community (Stage 2)**

##### **4.1.2.1 Major theme of ‘loss’ since diagnosed with mental illness.**

Most of the participants that responded to this portion of the research question focused on losses in the social domain (ten participants), with three participants describing a loss of ability to connect and/or communicate with people; and one more participant describing difficulty in interaction (due to symptoms) (Stage 2: participant 23):

“En dan somtyds maak hierdie siekte ook dat dit baie moeilikheit is. Want ek bedoel, die geraas in jou kop binne, dit maak dat jy het nie lus vir niemand nie, jy stres vir almal.”

Loss of friends was a significant loss for two participants, and one of these participants, together with two others, spoke about loneliness. Loss of acceptance and rejection were identified by three participants, and for one, this was connected to loss of employment (participant #2:25):

“Toe ek ’n job gehad het het almal my accept, maar nou het ek nie ’n job nie, nou word ek ge-reject en ek voel soos ’n second class citizen.”

Some participants also mentioned stigma, and felt that the manner in which other people reacted towards them (i.e. in a judgmental manner) hindered their recovery, as it affected their self-esteem. As one participant reports (participant #2:16):

“because after you got your illness, you are on your medication and you recover to be the normal person that you were before, but people still think you are mad, you do not know what you are doing, you are doing the wrong thing and things like that.”

Four more participants spoke about the loss of employment, one saying that permanent employment was no longer an option for him because of his hospitalisation. For another participant, her dreams of becoming a “successful person” as a police social worker were shattered. One participant connected employment with normalcy, and linked lack of access to employment to stigma; in this she included other people’s lack of belief in her capabilities (participant #2:27):

“I often sort of have feelings of I would like to break away and get a job, and live my life as normally as possible, but once up against the stigma of the illness... And the fact the public at large are not ready to accept mentally ill patients – they are full of preconceived ideas, and I actually do not feel I want to disclose my illness, because immediately they think, ‘oh, how is she going to be able to look after my children’, or ‘how is she going to be able to cope in this job’. You know, they jump to the worst conclusions about one’s illness.”

Five participants reported losses in terms of an intrapsychic disability. Two participants (in the same group) reported a loss of cognitive ability, which included a loss of clear, logical thinking or “cleverness”, often influenced by poverty of thought and severe memory difficulties.

According to a participant (#2:23):

“Hierdie skisofrenie is nie ‘n siekte nie, en iets wat mens kan mee speel nie. Want soos ‘n mens kan sê, dit gaan gepaard met geheue verlies, en baie kere dink die mense dat jy is van

jou verstand af, maar dit is nie eintlik so nie. Dit is net dat ‘n mens vergeet baie dinge. Soos wat ek nou voel op die oomblik, voel ek my kop voel leeg, daar is niks in nie. Soos my doel was gewees om eendag... kyk, jy kan aflei van my praat, ek wil baie dinge probeer sê, maar soos dit, hoe kan ek sê, my gedagte is vergeterig – dit vergaan, my gedagte.”

This participant also spoke about a loss of identity, reporting a sense of loss of self and a wish to be without the illness:

“Ek vat dit van my af, ek is skisofrenies siek, en dit is nie ‘n lekker siek nie, want somtyds dink jy maar net, jislaaik, kan jy nie maar net doen – tot jy net normaal kan wees, soos iemand anders wat soos jy miskien nog, sê maar, nog op skool gewees het nie. Jou lewe wat jy vooruit gesit het is net afgesny met hierdie siek. En jy dink, as hierdie siek nou nie met jou plaasgevind het nie, jy sal ‘n beter persoon vandag gewees het.”

Both this participant and another participant (in the same group) spoke about a loss of free will (participant #2:24):

“... die stemme, they enter our minds, they are going to... they make us think we do whatever they want us to think we will do, taking away our... free will.”

The above participant reported delusions and a lack of reality testing that were disturbing to him, saying that sometimes he realises his thoughts are wrong and that they lead to becoming ill. One participant reported decreased tolerance of noise, and another, loss of energy and motivation, which she felt threatened her future. For two participants, a loss of dreams and hopes for the future was an important significant change. In one case this was related to work, and in another, to marriage.

For two participants the disability (linked to memory problems) represented a decreased opportunity to participate in any learning activity. For two other participants, a significant change was the loss of the ability to live independently. Most of the participants live with family members.

#### 4.1.2.2 Responses of participants according to the domains identified as outcomes of PSR

Table 2

*Participants' Responses*

	Social	Personal	Learning	Living	Work
Number of participants who responded in this domain	28	18	10	3	5
Number of participants whose first response was in this domain	18	9	1	0	1

*Note:* Total number of participants who responded = 29

Many participants responded in more than one domain. Three participants responded in four domains, six in three domains, fourteen in two domains and six in one domain only.

Eleven participants responded in both the social and personal domains. Five participants responded in the social and learning domains. Five participants responded in all three of these domains. The six participants who responded in one domain only reported changes in the social domain, except for one participant whose most significant change was on a personal level.

##### 4.1.2.2.1 Social connection and interaction

Outcomes in terms of social connection and interaction were referred to by all but one participant as the most significant change since accessing a PSR programme. In general, meeting people and socialising was an important benefit, for which the programme was responsible. Participants elaborated in this domain, phrasing it differently and focusing on different sub-themes. Thus, the strongest emerging narrative was in the domain of socialisation, which included the following subthemes:

- improved interpersonal interaction and activity;
- the associated benefits of a supportive community; and
- improved social skills.

The subtheme of improved interpersonal interaction and activity included:

- having somebody to talk to;
- gaining friendships;

- increased ability to relate to others;
- increased ability to communicate and engage in conversation; and
- opening up, expressing one's feelings and sharing oneself.

The subtheme of positive benefits associated with a supportive community included:

- the notion of a safe space;
- an increase in a sense of belonging; and
- the normalisation universality provided by a group.

Some people included various sub-themes. According to one participant (# 2:1) in the Fountain House group:

“Fountain House has helped me so much, and I am really grateful for the opportunity to have come to Fountain House. I do not want to say that I have met friends; I would like to say that I have met my family. I have never thought of myself as a talkative person, because I was a very shy person. And it amazed me to see how many friends I have collected over the years at Fountain House, so they have also helped me a lot. I did not have to be on my own anymore, I could sit in a group of people and they would listen to what I have to say. So Fountain House has been very good to me, and it is a place away from home.”

Another participant (#2:9):

“Fountain House is just a little paradise, heavenly – it's a place where you can get a relief. A place where you can just – if you feel like crying, you can even cry, because as some of us have schizophrenia, mental illness – we have some problems that sometimes you think back, make your mind to rewind and think about what happened, and it just makes you feel terrible. This is the place to cry, smile, laugh – it's a place just to express your feeling and there are quite a lot of people who can assist you in any circumstance of life, and show you the way to get through to whatever.”

A third participant (#2:5):

“Then I come to know the people, all of them... Then we are starting to becoming to be friends, all of us, and then I know this place, and then I feel this is the place to be; and I like this place, because I gain a lot of experience from this place, you see.”

Many of the themes that emerged as significant changes in the domain of socialisation seemed to be directly related to the losses expressed since having been diagnosed with a mental illness.

There is convergence on many of the sub-themes between the two group settings of Stage 1 and stage 2 in the domain of socialisation, as reflected below (Table 3).

Table 3

*Similar sub-themes in terms of losses and outcomes in the domain of socialisation*

Losses	Outcomes
Loss of connection to others	Break isolation and loneliness
Loss of ability to communicate or converse	Ability to relate to others
Difficulty in interacting	Communicate with others & ability to engage in a conversation
	Opening up and expressing oneself
	Building friendships
	Accessing support
	Learning social skills such as co-operation and participation in the group context
	Safe space or supportive, nurturing space
	Sense of belonging
	Universality
	Support
	Integration with people from all walks of life

#### **4.1.2.2.1.1 Improved interpersonal interaction and activity**

The ability to relate to others and be interested in others was specifically referred to by three participants as an important achievement for them since accessing the PSR programme. Being of interest to others was mentioned by four participants as assisting them in the socialisation process. To have somebody to talk to was a significant shift that seven participants specifically

mentioned and the words “quality conversation” were used once. Opening up, expressing oneself, especially one’s feelings, and sharing about oneself and life was an important change for eight participants. According to one participant (#2:11):

“ People make you happy if they always ask how you are today. You feel like you are accepted in life. You feel happy and you feel content. You don’t feel hurt, because people hurt you really deeply.”

Two participants specifically mentioned that part of their change had been a move from isolation and loneliness towards companionship and friendship. Another two mentioned that to have shared experiences, enriching their lives, was an important change. Nine participants in total reported that they had gained friendship, which was the most significant change for them. As one participant expressed (participant #2:3):

“I am glad to talk to people. I am glad to have got friends at Fountain House. Friends in the location are not nice like the friends I’ve got here at Fountain House. I am better now I have got these friends.”

#### **4.1.2.2.1.2 Associated benefits of a supportive community**

Two participants spoke directly about their connection to the people and programme as an anchor in their daily lives. However, it was also implied in many other people’s stories. Nine participants felt an increased sense of belonging because of being part of the programme, and this strengthened their sense of self, increased their confidence and often lifted a negative mood state. According to one participant (#2:20):

“... the group, having been able to come and sit and relax, just be yourself, not any judgments by other people on how you behave, what they expect from you. And it helps the confidence when you are away. And when you are going through something bad, you think back on the Wednesday [the group], it picks you up, it helps you to cope through whatever it is at that stage you are going through, yes.”

Seven participants alluded to the PSR programmes as a safe space, where they find relief from their daily lives and problems and where they could relax, whereas no such space previously existed for them. Six participants referred to universality (that they were not the only ones suffering from a mental illness, and that others are in similar situations) as a benefit that contributed to their significant changes in the area of socialisation.

The support factor was an important change, specifically mentioned by seven participants. This included emotional support, motivation and encouragement, as well as inspiration through modelling of achievement or overcoming difficulties. According to one participant (#2:5):

“Nice people, they comfort you, and embracing, if maybe you are not in a good mood. Maybe you do not feel really happy, a little bit sad by something, by someone from home, but when you realise you are coming here at Fountain House, your life is changing again. You are changing when you are here. You feel happy, you see.”

#### **4.1.2.2.1.3 Improved social skills**

Seven participants reported that they had gained people skills, including the ability to engage in a conversation, to respond more maturely in social situations, to be understanding of and accepting towards people, and to co-operate in the group context. For two participants, integration with people from all walks of life was an important learning opportunity in the social arena. Two participants spoke about mutual respect as an important component of social interaction and friendship.

#### **4.1.2.2.2 Personal change**

The second important narrative emerging from this study was that of significant changes on a personal level, including increased confidence, self-esteem, gaining hope, improved positive attitude, self-knowledge and acceptance, increased motivation, increased vitality, increased motivation, increased awareness and interest in life, and purpose and meaning.

Outcomes in the domain of personal growth or gain were referred to by eighteen participants as an important change since accessing a PSR programme. Again participants elaborated in this

domain, phrasing it differently or focusing on different sub-themes. Some people included various sub-themes, for example the following participant (#2:26):

“It all made it worthwhile to continue with my life and all that. If there had been no Fountain House, I would just have gone back, I most probably would have remained very sick all my life. But now the quality of my life has improved so much, I cannot begin to tell you how happy – not happy, it is not the word, how my attitude towards life has, like, changed; from, like, negative to much more positive.”

Another participant (#2:1):

“And I have never been a person for goal-setting, but now I see myself wanting to do more of that, and finding out more about myself. So Fountain House has been real good to me... because it gives me so much confidence of myself, and it gives me strength. I mean, when there is people that have to go away, like the students or one of the staff – people have to go away – then they always ask me to say something, and I do not mind you know. And yes, I have spoken in groups of people; so yes, Fountain House has given me a voice.”

Improved self-esteem and increased confidence were the sub-themes most commented on in the personal domain (five participants commented on each sub-theme respectively, with two participants commenting on both). According to one participant (translated from Xhosa by a fellow participant) (#2:3):

“He is feeling so comfortable that he is at Fountain House. When he goes to the location, visiting his parents and family, the neighbours and other people who used to know him – they ask ‘hey, what is going on with you – you look beautiful and fat now’. He just tells them he is no longer smoking and drinking. That is all because of the place where he used to be in Fountain House, because of the members, the staff and everyone that used to encourage him in Fountain House.”

Another participant (#2:23):

“... vir my is dit soos ’n nuwe opening van ’n deur wat oopgegaan het. Ek is mos amper ingehok, sal ek sê, soos ’n dier in die hok in, maar vandat Suster Smit my verwys het hiernatoe is ek – ek kry amper, soos wat ek nuwe opportunities kry om uit te gaan en om dinge waar te neem en om goed te voel van myself.”

In terms of other sub-themes in the domain of personal growth and gain, two participants commented on their attitude changing from negative to positive, one further describing this in terms of gaining a “lebenslus” (vitality). Two participants described an increased awareness of and interest in life around them.

For two participants, important changes in terms of personal growth and gain were in the area of self-knowledge. Four participants described self-acceptance as an important change, especially in terms of limitations and medication. One of these participants reported that she used to be in denial about her illness. She used to believe that everyone else was wrong about her and she refused to acknowledge her illness, but she is now able to recognise her paranoia and has learned to manage it better. Another participant elaborated on self-acceptance in terms of honesty and self-respect. According to one participant (#2:10):

“And one thing is that before I came here there was a lot of trouble in my house, and I was the trouble of all that. You just need to look yourself in the mirror and say ‘is that really you – the guy with no smile on your face – the frowns in your face?’”

Further:

“Education is not for me. I can’t study – I can’t memorise things anymore, so what happens is I need to improve myself by taking care of some other things. This is much better for myself – this is healthier for myself, and this will not detriment myself. I will not disadvantage myself.”

Gaining hope was cited by four participants as an important change for them. One participant mentioned increased empathy, which had changed her into a “new person”, and another reported improved thinking as a gain. For one person, calmness brought on through participating in the programme was an important change, and for another participant, stability or wellness.

An important change for four participants was increased motivation – to get things done, as opposed to sleeping all day – and for two of these participants, this was linked to their day being meaningful. A third participant also felt the provision of meaning in their day was an important change, giving them something to do and somewhere to go. According to one participant (#2:20):

“When I think about the group, the most things that I gained – is motivation. Because before I came to the group I needed something to happen, like the phone to ring, or somebody knock on the door, the dogs bark, or my brother comes home. I need like a motivation like that for me to get up. So I just thank the Lord that I could come to the group and learn different things also. And it is a motivation to do things, you know. That is what I have learned.”

Another participant (#2:13):

“I have had a big change when I came to Fountain House. I used to be so lazy, not wanting to wake up in the morning, but when I used to come to Fountain House, I had to come early in the morning and be here and do some chores and helping with the admin – before I was in the kitchen. So then I saw a big difference when I came to Fountain House.”

There is convergence on some sub-themes between the two group settings of stage 1 and stage 2 in the domain of personal change, as reflected below (Table 4).

Table 4

*Similar sub-themes in terms of losses and outcomes in the domain of personal change*

Losses	Outcomes
Loss of cognitive ability	Self-esteem
Loss of clear thought	Confidence
	Insight/self-knowledge
	Self-acceptance
	Change in attitude
	Increase in motivation
	Hope

#### 4.1.2.2.3 Other narratives

Nine participants responded that significant change had occurred in terms of the domain of learning and that what they had learned in the programme was useful and helped them normalise their lives. Three participants identified understanding their illness as a major change for them. Four participants cited learning daily living skills as a different outcome or change; for example, working with money and budgeting. Three participants reported that learning coping skills, such as the ability to reduce stress, was a major shift for them. One participant claimed that improved problem-solving skills represented a change for him. Three participants responded that learning specialised skills – such as computer skills and cash register skills – was an improvement for them. As the following participant (#2:1) reported:

“Yes, and I am learning every day new things, I am doing the cash register when I do morning tea time and lunch time. I was always scared of that, not knowing. Because I was not confident enough working with money. But as the staff members started pushing me, pushing me – not in a bad way, but in a good way – so I decided, okay, I am going to take this task on and I am going to be strong in this. And when I started it, so I thought, oh my goodness, I can do this. It is still a bit scary for me, but I am getting used to it already, telling the people, please, please and let me do it in my time, not your time, yes. And I have learnt how to put on those gas stoves, because I never knew how to use a gas stove before. But now I am confident in that too. And yes, what I really want to say is, Fountain House has given me back my life in a big way.”

Another participant (#2:14):

“I need to talk to somebody who understands this line of thought, it gives me ideas which I try and use to kill the stress, make life easier. And it is through those I find I can handle things a lot easier. Otherwise I would not survive; I would not cope without their help.”

The theme of work was commented on by five participants. Two members reported a change after participating in the Fountain House Transitional Employment Programme (a part-time entry-level supported job placement scheme run by Fountain House, in partnership with corporate companies), one participant stating that it enable him to “build myself up from

scratch”. Another participant was in a learnership at the time of the study (a liaison between Fountain House and a government department). According to this participant (#2:28):

“I just wanted to say that I am 40 now, and you know the only thing that bothers me in life is that I have achieved nothing. And Fountain House has sent me on a learnership, which started probably about eight months ago. So I went to Siyaya, I have done admin business course, and I am currently working at the Department of Environmental Affairs every second week. And that is going to be that way for a year and a half, and then with the hope that I become permanent there, which would be fabulous. And I mean, that is just such an opportunity.”

Using their skills and contributing, either to the PSR community or volunteering in the real world, and being useful, created a sense of achievement for three participants. There is convergence on one sub-theme with regard to losses and outcomes between the two group settings of Stage 1 and Stage 2 in the domain of work, as reflected below (Table 5).

Table 5

*Similar sub-themes in terms of losses and outcomes in the domain of work*

Losses	Outcomes
A loss of the normalcy equated with work	Being productive or contributing, and feeling useful

For one participant in the Kraaifontein group, who felt that he could now cope with travelling by public transport, a major change was in the area of living. The theme of living was also touched on by two of the Kimber House residents, who felt they would not otherwise have been able to enjoy the quality of life that they currently had (living in a group home on their disability grant). The group home provided them with a secure, homely environment at an affordable cost. Living in a group home meant some major changes in terms of reduced stress: as one resident put it (participant #2:27):

“But, sort of, the major stress of life is taken off one’s shoulders like a weight because one is subsidised... And just the daily worries of enough money for rent and electricity

and phone and so on, that also is taken care of, and that is a tremendous weight off one's shoulders.”

### **4.1.3 Comparison within emerging data**

#### **4.1.3.1 Length of participation in programme**

Length of participation in the programme did not seem to influence the domain responses, as new and old members of the programmes responded in a very similar manner, and to the same extent. The natural verbosity of the participants appeared to affect how much information was given rather than the length of time they had attended the programme. Of the eight participants who did not contribute to the data, half were new members (less than a year) and the other half had been participating in the programme for a number of years.

#### **4.1.3.2 Gender**

Gender appeared to have no influence on the domain responses as expressed by the participants. Almost equal numbers of male and female participants responded in each domain, and no clear preference for sub-themes in each domain was expressed by either gender.

#### **4.1.3.3 Differences between Stage 1 and Stage 2 focus groups**

There was great congruence between the themes that emerged from the two sets of focus groups, Stage 1 and Stage 2. Some sub-themes were not directly expressed by both groups, although they were implied in the responses in different categories – either a loss through a gain, or vice versa. Stage 2 groups generated more sub-themes in each domain than the Stage 1 focus groups. Variations between the two groups may be accounted for by the fact the Stage 1 focus groups always comprised the same members, whereas the various focus groups of Stage 2 had different participants for each session. Thus the wider PSR community groups (Stage 2) had a greater representation of participants contributing to the data and adding different perspectives. Some important differences in sub-themes that were expressed are discussed below, keeping in mind that Stage 1 focus group consisted of the higher-functioning members of CCAB, while Stage 2 focus groups consisted of participants with various levels of functioning.

Some of the sub-themes differ from each other in terms of conceptual understanding. For instance, Stage 2 participants spoke about loss of friends and rejection, while CCAB members (Stage 1) included the intra-psychic processes inherent in the social process that may have been partly responsible for loss of friends; such as loss of social understanding, inability to trust, withdrawal, disconnection and loss of social skills (see Table 6 below). It is interesting to note that, with regard to the losses described by Stage 2 participants, the locus of control lies with the other rather than the self. This may have to do with their feelings of lack of agency and empowerment.

Table 6

*Different sub-themes emerging from Stage 1 and 2 focus groups in the socialisation domain*

Losses		Outcomes	
CCAB Focus Group	Wider PSR community Focus Groups	CCAB Focus Group	Wider PSR community Focus Groups
Inability to trust	Loss of friends	Trust	Meeting people and socialising
Loss of people/social skills	Loss of acceptance and rejection	Feeling understood	Interested in the other
Loss of social understanding			Shared experiences
Withdrawal and isolation			Learning social skills such as responding more maturely in social situations,
Disconnection with family members			understanding of and accepting towards people
			Mutual respect
			Connection serves as anchor

Learning skills, whether acquiring social skills (in table 6) or in the domain of learning (which includes daily living skills, coping skills, problem-solving skills) seem to be of more importance to Stage 2 participants. By contrast, Stage 1 participants (CCAB members, who may be further along the road to recovery, and who have more advanced skills, such as public speaking) take these skills for granted (as does the rest of humanity).

A clear distinction between Stage 1 and Stage 2 is that many of the personal losses for participants in Stage 2 focus groups were directly related to symptoms of the illness, as well as being closer to the devastating process of loss of self. On the other hand, the CCAB members

(Stage1) had a greater distance between themselves and their illness, and had achieved a far more positive sense of themselves, though they were still aware of the losses they had once suffered. Personal outcomes important for wider PSR community group participants (Stage 2) seem to reflect a survival of mental illness, rather than a personal growth process (See table 7 below).

Table 7

*Different sub-themes emerging from Stage 1 and 2 focus groups in the personal domain*

Losses		Outcomes	
CCAB Focus Group	Wider PSR community Focus Groups	CCAB Focus Group	Wider PSR community Focus Groups
Loss of understanding and conceptualisation	Poverty of thought	Ability to trust	Vitality
Loss of choice	Memory difficulties	Focus	Increased awareness and interest in life
Loss of confidence	Loss of identity	Realisation of own needs	Honesty & self-respect
Loss of dignity	Loss of sense of self	Goal-directedness	Meaning
	Loss of free will		
	Delusions		
	Lack of reality testing		
	Decreased tolerance for noise		
	Loss of energy or motivation		

**4.1.4 Summary of sub-themes according to domains**

All but one participant referred to outcomes in terms of social connection and interaction as a most significant change since accessing a PSR programme. In general, meeting people and socialising was an important benefit of the programme. Participants elaborated in this domain, and also phrased it differently and focused on different sub-themes. Thus, the strongest emerging narrative was in the domain of socialisation, including improved interpersonal interaction and activity, associated benefits of a supportive community, and improved social skills. The subtheme of improved interpersonal interaction and activity included having somebody to talk to; gaining friendships; increased ability to relate to others; increased ability to communicate and engage in conversation; opening up, expressing one's feelings; and sharing. The subtheme of positive benefits associated with a supportive community included the notion of a safe space, an increase of sense of belonging, and the normalisation provided by universality.

The second important narrative emerging from this study was significant changes in the domain of personal change; this included increased confidence, self-esteem, gaining hope, improved positive attitude, self-knowledge and acceptance, increase in motivation, increased vitality, increased motivation, increased awareness and interest in life, purpose and meaning.

The narratives in the domain of learning or capacity-building (for example, regarding gaining skills that the individual was deficient in, learning about their illness or gaining specialised or work skills) did not emerge strongly from the data. Significant change – in terms of gaining either daily living skills, coping skills, specialised or work skills, or an increase in motivation – was reported by a smaller number of participants.

Work did not emerge as a strong narrative, but access to meaningful activities and the opportunity to use skills and contribute was a meaningful narrative. This concurs with the literature concerning the importance of these aspects in recovery.

Only some of the residents living in the Kimber House group home contributed in the domain of living, referring to supported housing and the significant change of having a nurturing home environment. Thus, in the overall study this was not a strong narrative.

#### **4.1.5 Other themes (not directly related to research question)**

Family and medication play a huge role in the recovery of people with mental illness, and may be complicating factors when improvements in participants' quality of life are considered.

##### **4.1.5.1 Family**

Stage 1 focus group participants questioned the role of the family in the recovery process, and they discussed the manner in which the home environment affects the quality of life for people suffering from a mental illness. It was acknowledged that mental illness in a family member “can break the family”, but the support of one's family is an important foundation stone of the road to wellness, as people with a mental illness need love, patience and kindness (as does everyone else). An important issue that was flagged is that families need more awareness, and that denial on the part of family is detrimental to the recovery of people with mental illness. Trust within the

family was seen as an important precursor to trust of other people, which is vital to the socialisation process. Families were not seen as supportive by some participants in the Stage 2 groups and the PSR programmes were described by them as a haven from verbal abuse, shouting and insults in particular. Complaints were raised concerning not being understood by family, and as one participant (#2:27) reports:

“I think a lot of our problems become worse with the attitudes of our family towards us. Like my sister in Australia has said to me, why do you not write a book about your illness, so that people understand. And she often phones me in a state of anxiety, ‘are you alright?’ Or if I am challenging or a little bit too aggressive on the phone, she says, ‘have you taken your medicine?’ And it really irritates me, hey. It is just that their life is so ‘normal’ and one is regarded as abnormal. And who gives them the right to even make that judgment?”

#### **4.1.5.2 Medication**

Stage 1 focus group participants agreed that appropriate medication had a beneficial effect on their ability to cope. It stabilised them and provided a foundation for rebuilding their lives. Stage 2 focus group participants were unsure whether the medication was working for them or not. One participant acknowledged that he used not to take his medication regularly, in the hope that he could be well without it; but he eventually realised that he became sick every time, and that continuous medication was important in order to avoid hospitalisation. He has suffered from schizophrenia for 31 years, has been hospitalised on 4 to 6 occasions (most recently during this year) and still sometimes lapses into non-compliance.

#### **4.2. Experience for participants**

Speaking into a microphone (used as a recording device, due to the accidental switching off of the digital recorder when it was passed around) was difficult for some participants. According to one participant she felt pressurised by everybody’s expectations and forgot what she wanted to say. Others were also nervous initially, but felt their fears were removed by the supportive nature of the process, especially since the group consisted of familiar faces. One participant felt depressed after disclosing a traumatic history, and was debriefed after the group session.

Participants generally described their experiences of participating in the research as positive. Some participants felt that working constructively on a project increased their self-esteem. Some felt it increased their sense of pride and confidence. For others, sharing their story and being afforded an opportunity to talk about their issues was a privilege. Learning from other peoples' experiences, and what had changed for them, gave many (especially new members) insight into the benefits of the programme, which created excitement about attending. Participants were generally grateful for the opportunity, felt excited and honoured to be part of the process, and some expressed a sense of relief. One participant felt that looking back allowed him to see things from a different perspective. Many people felt they were contributing to a better understanding of their illness.

#### **4.3. Problems encountered**

Initially negative symptoms (e.g. avolition) may have affected the level of interest in the research process, but with a more direct approach, participants were easily secured. However, this was concerning, because it reflected the issues of power that the researcher was attempting to guard against. When asked directly whether they would like to attend the group that was about to take place (at Fountain House), few refused. The researcher was also known to many of the participants and this may well have affected their willingness to participate.

Many participants presented with memory problems; some could not remember the question or topic for discussion, while others could not remember what they had said previously. This was despite a poster on the wall displaying the research question, and thorough explanations at the commencement of each group. One participant became paranoid, and questioned the researcher's identity and the aim of the research, notwithstanding the thorough introduction given at the start of the group. Many participants were over-inclusive and tangential in their accounts, and were easily distracted by questions asked for clarification. Participants may have been swayed by previous participants' contributions. This may have led to richer data on specific aspects, possibly to the exclusion of other data that participants may have provided or have given as a first response.

#### **4.4 Comparison between outcomes of this study and programme aims**

(See aims and objectives in the programme description on pages 11-13)

##### **4.4.1 Socialisation**

Participants appeared to value the activities presented by the CMHS PSR programmes in the life area of socialisation. Ninety-six percent of the sample responded with significant changes in the domain of social connection and interaction, with this being the first response of 62% of the sample.

In terms of the programme goal of providing support and developing support networks, to enhance the socialising of its members, 69% of the sample reported improved interpersonal interaction and activity. For 24% this meant merely having somebody to talk to, for 31% it meant friendship and for 28% it was about opening up, expressing one's feelings, and sharing about oneself.

In terms of the programme goal of providing a safe and secure environment, 65% of the sample responded that they had benefited from this supportive community. Twenty-four percent of the sample referred directly to the notion of a safe space, where they can find relief and relaxation, while 31% of the sample reported an increase in their sense of belonging, and 21% referred to the theme of universality.

In terms of the programme goal of development of social skills, 24% of the sample referred directly to having gained specific social skills.

It appears that the programme is generally meeting its aims in terms of the life area of socialisation, even though aspects may be expressed differently by different individuals, and different facets may be accentuated.

##### **4.4.2 Personal Growth**

Although personal growth is not a goal of the programme per se, it is an underlying assumption that participation in programme activities will increase a member's confidence, self-esteem and

self-worth, all of which are attributes of a positive sense of self. Sixty-two percent of the sample reported significant changes on a personal level contributing to a positive sense of self, including increased confidence and self-esteem; gaining hope; improved positive attitude, self-knowledge and acceptance; increase in motivation, vitality and awareness; and interest in life, purpose and meaning. Similarly, 'providing hope' is not explicitly stated as a programme goal, but is part of the philosophy of the programme.

#### **4.4.3 Learning**

Improvements in the life area of learning were reported by 35% of the sample, most having already responded regarding the social or personal domain. It may be that the value of supportive relationships overshadowed all other areas of gain, or alternatively that programme activities did not lead to a significant change in this domain.

In the programme's psycho-education activities, the aim is to increase members' knowledge and insight concerning their illness. A very small percentage of participants identified understanding their illness as a significant change for them. When grouped together with related themes (an increase in self-knowledge and self-acceptance), which may or may not have included understanding of the illness as an element, 21% of the sample reported improvement. The lack of knowledge about their medication seems to need addressing for some members of the stage 2 focus groups.

Skills development is another major component of PSR, and 31% of participants reported a significant change in terms of gaining either daily living skills, coping skills, specialised or work skills or an increase in motivation.

#### **4.4.4 Work or meaningful activities**

Securing employment opportunities is a programme goal of Fountain House specifically. Only a small percentage of the sample spoke about work in terms of a significant change due to participation in the programme. Eighty-eight percent of the sample are unemployed, but most have worked previously, 29% having worked for more than 10 years. Few of the working members of the programmes participated in the study. Their participation may have resulted in

different data. Having access to meaningful activities (and having the opportunity to use their skills and contribute) was important to 21% of the study participants, which is an important component of the programmes. It may be that most participants responded to what was real and immediate in their lives. The question was about the most significant change; which, in this area, is not as accessible to participants as it is, for instance, in the area of socialisation.

#### **4.4.5 Living**

The PSR programmes tries to address the life area of living through various poverty and alleviation activities, but not a single response was in this area. Kimber House, as a group home, has the goal of providing a safe, secure, comfortable, supportive and affordable home environment in the life area of living. Fifty percent of the respondents in the Kimber House sample (four people), which translates to 18% of the residents, cited having a homely environment as a significant change.

## **CHAPTER 5: DISCUSSION & CONCLUSION**

### **5.1 Discussion & Conclusion**

With the improvement of medication, mental health policies aimed at community integration, and the growing realisation that people may be able to recover from mental illness, the question of how the mental health system can assist people with mental illness to attain their highest level of mental health and best possible quality of life is very important. Recovery can be defined as a significant, positive change in a person's life, which is why the question "What has been the most significant change in your quality of life since accessing PSR programmes?" was deemed most appropriate.

The recovery paradigm emphasises that the focus needs to be on the preferred outcomes of people with mental illness themselves, and their subjective experiences, rather than only the objective judgment of mental health professionals. Focus groups were the preferred method of data-gathering, not only to give service-users a voice, but also to draw on the strengths of participants being in supportive communities. Financial pressures dictate that programme outcomes must be supported by evidence-based research, which raises the issue of how best to measure quality of life outcomes. The value of open-ended, participatory qualitative research lies in clarifying what individual participants of programmes consider to be important outcomes. The comparison of these outcomes with programme aims demonstrates the effectiveness of the programme under consideration. When the two themes (positive personal growth, and interconnectedness with others) which emerged as valued outcomes were compared with themes from the rehabilitation and recovery literature, they were found to be in line with international findings regarding the most important outcomes to people with mental illness.

Studies that have investigated the key components deemed by service-users to be helpful in the recovery process, the preferred outcomes of service-users gathered from participation in programmes, and actual outcomes of programmes aligned with recovery principles, all point to similar effects. A positive social connection fosters trust and a sense of belonging and instils hope (Anthony, 1993; Herman et al., 2005; Russinova, 1993). This may be a key component in the recovery process and is crucial, as the loss of relationships and valued social roles may be the

most devastating impact of a mental illness due to the resultant destruction of self-esteem, self-worth, and confidence (Chovil, 2005; Michalak et al., 2006; Stein et al., 2005; Starkey & Flannery, 1997). The re-building of a positive sense of self is closely linked to the availability of supportive relationships and communities (Herman et al., 2005; Kahng & Mowbray, 2005; Mancini et al., 2005; Sells et al., 2004). The findings from this study concur with the themes that emerged from the literature. The strongest emerging narrative from this study was in the domain of socialisation, which included improved interpersonal interaction and activity, the associated benefits of a supportive community, and improved social skills.

A strong sub-theme that emerged from this study was that of improved interpersonal interaction and activity, which included the following: having somebody to talk to; gaining friendships; increased ability to relate to others; increased ability to communicate and engage in conversation; and opening up, expressing one's feelings, and sharing about oneself. This is important, as these aspects were cited by participants as losses that they experienced when they first became ill with a mental illness, which corresponds with the literature (Chovil, 2005; Hensley, 2005; Starkey & Flannery, 1997). This, then, seems to indicate the existence of some reclaiming and recovery process.

Another strong sub-theme that emerged which indicated a significant change was that of the positive benefits associated with a supportive community, including to the notion of a safe space, an increase in sense of belonging, and the normalisation provided by the factor of universality.

A theme taken from the literature as a preferred outcome for people with mental illness, as well as being a key component in the recovery process, is social connection and interaction (Anthony et al., 1993; Anthony, 2003; Bond et al., 2004; Craig, 2006; Davidson et al., 2009; Deegan, 1988; Glover, 2005; Herman et al., 2005; Jacobson, 2001; Jenkins & Carpenter-Song, 2005; Michalak et al., 2006; Mead & Copeland, 2000; Ochocka et al., 2005; Onken et al., 2007; Ridgway, 2001; Sells et al., 2004; Smith, 2000; Spaniol & Gagne, 1997; Wong et al, 2009). It seems that, without supportive relationships, building a positive sense of self (another strong theme in the literature) is not possible (Davidson et al., 2003; Sayce, 2000). The findings from this study provide further evidence that most people value improved and increased socialisation as a significant outcome. After all, we are social animals, and do not exist in a vacuum, but in the

gaze of “the other”. It is not surprising, then, that many people cite improved socialisation as a significant change, since mental illness has a profound impact on an individual’s connection to the world, which is further perpetuated and exacerbated by stigma. Unfortunately stigma, or rather discrimination, goes hand in hand with mental illness, and is part of the process of ‘othering’, which directly affects a person’s sense of belonging and acceptance as a valuable member of society.

It is significant that improvement in social connection was linked to participation in the PSR programme; it seems to be the bedrock on which recovery is built. A service that aims to improve the quality of life for people with mental illness has to have the basic building blocks in place, otherwise other goals and aims would be impossible to reach, or could only be attained on a superficial level. Research on PSR programme outcomes provides support for the value placed on socially supportive relationships, and on the personal aspects of recovery. Findings from this study concur with previous findings (Bracke, 2001; Corring, 2002; Cradock et al., 2002; Herman et al., 2005; Luk & Shek, 2008; Pilling, 1991).

Evidence is accumulating in support of the fact that opportunities for participation in valued meaningful activities (not necessarily work) within a social context may be vital to building a positive sense of self in the recovery process (Brown et al., 2008; Herman et al., 2005; Mancini et al., 2005; Sells et al, 2004). CMHS PSR programmes claim and aim to provide a range of ‘meaningful activities’, with the underlying assumption that participation in these activities will increase a member’s confidence, self-esteem and self-worth.

The second important narrative emerging from this study was significant change in the personal domain. This included increased confidence and self-esteem; gaining hope; improved positive attitude, self-knowledge and acceptance; increased vitality, motivation, awareness and interest in life; and purpose and meaning, which is consistent with the greater body of literature (Davidson et al., 2009; Deegan, 1988; Jacobson, 2001; Mancini, Hardiman, & Lawson, 2005; Ochocka et al., 2005; Ridgway, 2001; Russinova, 1999; Smith, 2000; Townsend & Glasser, 2003). This provides further evidence for the link between participation in meaningful activities with others and a positive sense of self.

Narratives in the domain of learning or capacity-building, whether in gaining skills that the individual was deficient in, in learning about their illness or in gaining specialised or work skills, did not emerge strongly from the data. Significant change in terms of gaining either daily living skills, coping skills, specialised work skills, or an increase in motivation was reported by only a small number of participants. Skills development is a key component in PSR programmes, for the purpose of overcoming the disability that affects the daily living, functional, coping, social and work skills underlying the individual's engagement in the world. Although this did not come through strongly in the narratives, skills development is generally acknowledged as an important foundation, on which a sense of valued self is built, and this aspect could well be deserving of further investigation.

'Work' as a narrative was almost absent, but access to meaningful activities and the opportunity for participants to use their skills and contribute was a meaningful narrative, concurring with the literature regarding the importance of these aspects in recovery (Herman et al., 2005; Mancini et al., 2005; Luk & Shek, 2008; Russinova, 1999; Smith, 2000).

Only some of the residents living in Kimber House (a group home) contributed to the theme of living, referring to supported housing and the significant change of having a nurturing home environment.

Subjective quality of life improvements for most participants in this study included facets of a positive sense of self, as well as valued socialisation experiences. This means that the following programme aims seem to be met: providing support and developing support networks, enhancing the socialising of its members and building social skills; providing a safe and secure environment; fostering belonging; and providing hope. Although personal growth is not a goal of the programme per se, it is part of the philosophy of PSR, and it appears that the programme is strong in this component. The skills development and capacity-building component of the programme received much less attention than the two main narratives, although a third of the study did report change in this area. The two remaining components – the life areas of living and work – were under-represented in the discussions.

It is important to keep in mind that participants were not asked to respond in terms of all the programme components and all the goals of the programme, nor were they required to respond in terms of all the domains. They were asked for their personal stories of significant change – not all the changes necessarily, but the most important. Even though some people responded with several changes, it is understandable that social interaction and a positive sense of self emerged as the strongest themes, being the most immediate and accessible in terms of peoples' lived experiences. Many of the participants received only a disability grant and were subject to extreme poverty (except for the residents of group homes). Thus, they had experienced little improvement in terms of living environment. The high number of unemployed participants in the study may have led to the under-representation of work as a theme. However, feeling useful emerged as a meaningful theme, relating to being able to contribute – but not necessarily in the economic arena.

This study provides further evidence in support of the personal aspects of recovery as well as the value of socially supportive relationships. The purpose of the study was to look at the service-users' outcomes achieved through participation in the PSR programme, and to compare whether they are in line with programme objectives. Subjective quality of life improvements for most participants in this study were in the social and personal domain. The CMHS PSR programmes – in line with the philosophy of PSR and recovery principles – seem to be providing safe spaces for people with mental illness, and to be creating opportunities for meaningful interactions with others, which enhances the individual's confidence and self-esteem, while building social skills. It appears that the psychosocial rehabilitation programme for people with severe mental illness presented by the Cape Mental Health Society benefits its participants in a very definite manner. The vision and aims of PSR as adopted by this programme are indeed reflected in the lived experiences of the service-users, therefore rendering it a robust programme.

## **5.2 Strengths and limitations of the study**

A comparative study between members accessing the programme and those who do not access any PSR service might present a more accurate picture as to whether PSR achieves better outcomes or not. However, asking service-users to reflect on whether their life was different

before and after accessing PSR services has demonstrated that service-users experience subjective improvements in their quality of life due to participation in the PSR programme. The study therefore constitutes more a non-causal evaluation as to whether service-users value and perceive benefits from participating in PSR, as opposed to proving a direct link between programme activities and outcomes that are measurable and observable to others. An important strength of the study is that it accesses perceptions of service-users from varied demographic backgrounds and levels of functioning.

The fact that the researcher was previously employed as Programme Co-ordinator for Fountain House may have led to some bias, in that certain findings may be emphasised while others are ignored at the expense of an unbiased exploration of the case study (Willig & Stainton-Rogers, 2007). Even so, the researcher's specific knowledge afforded important access and insight, and a systematic analysis of the data, using matrixes with direct quotes, allowed for objectivity, checking and verification.

### **5.3 Recommendations**

The value of the social context in providing hope of possible recovery is an important factor to be considered in respect of individuals' first contact with the mental health field. Mental health service-providers must always be mindful of the impact of their presence on the patient. They may unknowingly send powerful messages intensifying stigma, as opposed to taking the vulnerability of the patient into account.

PSR needs to be initiated early, as an intervention with a clear message of hope. Often people only access rehabilitation services after years of suffering and accumulated losses. Stigma influences the individual's acceptance of their illness, which leads to denial. Acceptance is part of the personal recovery journey that each person makes, and consequently it is important that the message of hope is communicated as early as possible. But the question: "what can be hoped for?" needs to be asked in light of the numerous variables that could impact on the course of an individual's mental illness, including pre-morbid functioning, and availability of resources, both internal and external? Besides the problems of monitoring of medication, there is often poor follow-up after hospitalisation. There is clear empiric evidence for the fact that the despair that

so often accompanies a mental illness can be replaced by steps towards recovery and a better quality of life. Unfortunately recovery is not strongly promoted in the South African context, and often the hospitalised person faces a dismal future. Recovery does not occur in a vacuum; socio-economic factors may undermine the hope (for service-users and service-providers alike) of the opportunity for a better life. However, the disempowerment and despondency that people with mental illness often feel has many roots.

The impact and prevalence of poverty plays a huge role in the reduction of quality of life for people with mental illness. Poverty, especially in South Africa, is an important variable to consider in the assessment of quality of life. Family dynamics compound the problem; they are often a source of conflict, due to stressors such as the impact of the mental illness, but also because of poverty and lack of adequate income from the individual with the mental illness. Exposure to repeated trauma due to living in violent and unsafe environments increases the complexity of the problem.

These issues aside, even the search for the best-fit medication is fraught with problems. Availability and accessibility of medication is an issue that needs urgent attention. In light of the role relationships play in recovery, important issues are the willingness of the psychiatrist to discuss medication with the patient, as well as the patient's lack of assertiveness in demanding the same.

Recovery from mental illness is not a simple, straightforward matter. This presents us with the dilemma of how best to help people with mental illness. The findings of this study demonstrate the effectiveness of psychosocial rehabilitation as a method of intervention. It is therefore recommended that increased funding from the South African government be appropriated to the development of such programmes in South Africa.

Since it is the relationship that is the critical factor in recovery, an important aspect to consider is the impact that working with people with mental illness may have on mental health professionals. Burn-out is a real risk for mental health professionals. Considering the current ratio between numbers of mental health professionals and service-users in day hospitals and at tertiary level as well as the paucity of referral opportunities, it is imperative that psychosocial

rehabilitation programmes are extended beyond what is currently available. It is not only a psychiatrist or psychologist's diagnostic and clinical skills that can aid recovery, but basic human interaction, which can be provided by anyone with high levels of empathy and a non-discriminatory approach, clearly plays a vital role. Thus, psychosocial rehabilitation programmes may be staffed by less expensive non-professionals, provided proper training, adequate support structures and supervision are in place.

In terms of research, no studies of the effectiveness of PSR programmes in the South African context have been published. This study may be able to guide future researchers as to which outcomes are deemed important by service-users.

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## 8. APPENDICES

### Appendix A:

Table 8

*Optimal outcomes for persons with serious mental illness.*

PHYSICAL DIMENSION	SELF DIMENSION
Improved health	Increased self-awareness
Increased energy	Increased self-acceptance
Improved stamina	Increased self-esteem
Improved fitness	Increased inner strength or empowerment
Improved sleep	Improved self-control
Increased physical relaxation	Increased sense of responsibility
Decreased physical pain	Increased capacity to tolerate uncertainty
	Increased openness
	Increased capacity for self-expression
EMOTIONAL DIMENSION	SOCIAL DIMENSION
Increased emotional stability	Feeling accepted or supported by others
Increased capacity for mood containment	Improved social skills
Increased capacity for emotional self-regulation	Decreased social isolation
Increased calmness	Increased sense of trust
Decreased social anxiety	Increased capacity for empathy
Increased sense of safety or security	Increased tolerance of others
Increased capacity for emotional expression	
Increased capacity for release of negative feelings	
Decreased impulsivity	
COGNITIVE DIMENSION	SPIRITUAL DIMENSION
Decreased negative thinking	Increased hopefulness
Decreased delusional thinking	Increased connection
Decreased racing thoughts	Increased sense of meaning or purpose
Improved concentration	Sense of spiritual fulfilment
Improved memory	Sense of inner peace
Increased coping behaviours	Increased capacity for forgiveness
OVERALL FUNCTIONING	
Decreased self-destructive behaviour	
Improved adaptive behaviour	
Improved vocational capacity	
Improved capacity for self-care	
Improved coping capacity	
Increased sense of well-being	

Note *Psychiatric Rehabilitation Journal*, 29(4), 241–250

**Appendix B: Demographic Information**

Table 9

*Breakdown of basic demographic information of participants*

	Personal data	Number of Participants	Percentage of sample
Sex	Male	21	57 %
	Female	16	43 %
Race	Coloured	19	51 %
	Black	9	24 %
	White	8	22 %
	Indian	1	3 %
Marital status	Single	29	78 %
	Divorced	4	11 %
	Married	4	11 %
Age (years)	18 – 25	4	11 %
	26 – 30	4	11 %
	31 – 35	8	21 %
	36 – 40	7	19 %
	41 – 45	3	8 %
	46 – 50	5	14 %
	50 +	6	16 %
Highest level of education	Below grade 6	3	8 %
	Grade 6 & 7	3	8 %
	Grade 8 & 9	9	24 %
	Grade 10 & 11	10	27 %
	Grade 12	8	22 %
	University education	3	8 %
	Undisclosed	1	3 %
Living with	Family	23	62 %
	Group home	12	32 %
	Alone	2	6 %

Table 10

*Breakdown of employment and income status of participants*

	Personal data	Number of Participants	Percentage of sample
Employment status	Unemployed	33	88 %
	Full-time employment	1	3 %
	Part-time employment	1	3 %
	Learnership	1	3 %
	Retired	1	3 %
Previously employed?	Undisclosed	5	15 %
	Never employed	2	6 %
	Worked in the past (not clear how long)	8	23 %
	Worked previously, less than one year	5	15 %
	Worked previously, 1 – 4 years	1	3 %
	Worked previously, 5 – 10 years	3	9 %
	Worked previously, 11 – 20 years	8	23 %
	Worked previously, 20 + years	2	6 %
Disability grant	Yes	32	86 %
	No	5	14 %

Table 11

*Breakdown of information regarding the illness of participants*

	Personal data	Number of Participants	Percentage of sample
Diagnosis	Undisclosed	3	8 %
	Schizophrenia	19	51 %
	Schizoaffective	2	5,5 %
	Bipolar Mood Disorder	7	19 %
	Major Depressive Disorder	4	11 %
	Other primary diagnosis (Intellectual Disability / Epilepsy)	2	5,5 %
	Other diagnosis (secondary to primary diagnosis – PTSD, Dysthymia, alcoholism))	3	8 %
	Borderline Personality Disorder (in addition to mental illness)	2	5,5 %
	Years of illness (35 participants – excluding other diagnosis)	Less than 2	2
2 – 5		6	17 %
6 – 10		4	12 %
11 – 15		5	14 %
16 – 20		5	14 %
20 +		7	20 %
Undisclosed		6	17 %
Frequency of hospitalisations (35 participants – excluding other diagnosis)	Zero	1	3 %
	Once	8	23 %
	2 – 3	12	34 %
	4 – 6	8	23 %
	More than 6	2	6 %
	Undisclosed	4	11 %
Last time hospitalised	During this year (2008)	3	8, %
	2 – 5 years ago	10	30 %
	6 – 10 years ago	6	17 %
	11 – 15 years ago	3	8, %
	16 – 20 years ago	3	8, %
	20 + years ago	2	6 %
	Undisclosed	8	23 %

Table 12

*Breakdown of information regarding participants' participation in the programme*

Years of participation in the programme	Less than a year	15	40 %
	2 – 5	5	13 %
	6 – 10	7	19 %
	11 – 15	3	8 %
	16 – 20	2	6 %
	20 +	3	8 %
	Undisclosed	2	6 %
Regularity of participation	Once a week rainbow group or Fountain House	15	40 %
	Couple of times per month Rainbow group or Fountain House	1	3 %
	Almost every day Fountain House	12	32 %
	2 -3 times per week	7	19 %
	Few times a year	1	3 %
	Undisclosed	1	3 %
	\Participants accessing more than one programme	Total	11
Rainbow group members accessing Fountain House		5	13,5 %
Rainbow group members accessing CCAB		6	16 %
Fountain House members accessing Rainbow		3	8 %
Fountain House members accessing CCAB		2	5,5 %

## CONSENT FORM

1. **Invitation and Purpose**

Thank you for accepting the invitation to take part in this research study. The aim is to collect people's personal stories on living with a mental illness and taking part in the groups. I am Denise Grobbelaar from the University of Cape Town, previously Programme Co-ordinator of Fountain House. This study is not funded by any organisation and does not form part of Fountain House and Cape Mental Health Society.

2. **Procedures**

You will be expected to take part in the discussions during a one-hour focus group. A small number of questions will be asked for you to think about and tell your story. Participants may ask each other questions. A follow-up group may be necessary.

3. **Benefits**

This study is not designed to benefit you; however the opportunity to disclose your own unique experiences may be experienced as empowering. The knowledge we will gain from the study will be used to document the stories of people living with a mental illness.

4. **Risks, Discomforts & Inconveniences**

This study poses low risk to you and will not harm you in any manner. The main risk is that you might experience emotional or psychological discomfort as disclosure about certain aspects of your life may make you feel uncomfortable or embarrassed. You may later regret having disclosed certain aspects.

6. **Privacy and Confidentiality**

All research material; recorded interviews as well as transcribed interviews will be kept by me and confidentiality is assured. I will take strict precautions to safeguard your personal

information throughout the study. Extracts from the focus groups may be published, but no identifying information will be included, thus your anonymity would be assured.

7. **Money Matters**

There is no financial reward for your participation in the study.

9. **Questions**

If you have questions, concerns, or complaints about the study or questions, please contact Denise Grobbelaar at [denise.grobbelaar@gmail.com](mailto:denise.grobbelaar@gmail.com)

10. **Signatures**

I have been informed about this research study and understand its purpose, possible benefits, and risks. I agree to take part in this research as a subject. I know that I am free to withdraw this consent and quit this project at any time, and that doing so will not have any consequence for me.

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Subject's Signature                      Date

\_\_\_\_\_ has been informed of the nature and purpose of the procedures described above including any risks involved. He or she has been given time to ask any questions and these questions have been answered to the best of the investigator's ability. A signed copy of this consent form will be made available to the subject.

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Investigator's Signature                      Date