HUMAN OCCUPATION IN THE CONTEXT OF CHRONIC POVERTY AND PSYCHIATRIC DISABILITY

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DECLARATION

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Date: 27 December 2009

ABSTRACT

This study, within the fields of occupational therapy and occupational science, describes the occupations of isiXhosa-speaking individuals with longstanding histories of mental illness living in chronic poverty. Occupation refers to the daily tasks and purposeful activities which, in occupying people's time, establish the patterns of their lives and give expression to their roles, identity, interests and abilities. The aim of this study was to describe how poor households and persons with psychiatric disability living in those households coped with their circumstances and how they viewed, orchestrated, drew meaning from and attributed purpose to the everyday things they did, in particular the self-identified, primary income generating occupation of the disabled person. The research questions elicited information about the genesis, characteristics, meanings and functions of occupation, in particular those occupations performed by the disabled member that contributed to the survival of the household.

Using case study methodology, the research involved prolonged engagement with five households living in a peri-urban, informal settlement on the outskirts of Cape Town, South Africa. Qualitative data about occupation was derived through demographic screening, multiple interviews with key informants in each household, participant observation and focus group discussion. In addition, discussions were held with mental health professionals familiar with the context and the Xhosa culture. Four forms of data analysis and interpretation (Kavale, 1996; Stake,1995) were applied to develop substantive case studies: condensation (identification of major organising ideas); categorisation (thematic categorical aggregation); patterning (narrative structuring) and generalisation (naturalistic interpretation). In addition, discussions were held with mental health professionals familiar with the context and the Xhosa culture. Four forms of data analysis and interpretation (Kavale, 1996; Stake, 1995) were applied were applied to develop substantive case studies: condensation (identification of major organising ideas); categorisation (thematic categorical aggregation); patterning (narrative structuring) and generalisation (naturalistic interpretation). Thematic descriptions of the basics of occupation are used to illustrate the various ways participants negotiated the challenges of life at the margins of society through the ordinary things they did everyday. Cross case analysis provided insights into the financial and social costs of mental illness as well as the strategies, embedded in occupation, adopted by participants in dealing with their circumstances.

The central thesis of this dissertation is that psychiatrically disabled people, as economic actors functioning in complex structural, social and occupational matrices, contribute in

paradoxical ways to the survival of their households. While their illness behaviour may increase the vulnerability of the household from time to time, they nevertheless facilitate its functioning either as providers of a disability grant; as contributors of additional labour or as productive income generating agents. The individual, the social and the structural are co-constituted in what poor and disabled people are able to do everyday. The less resources that are available in the occupational form, the more effort is needed to perform occupations and the more reliance is placed on the informal relational economy. Relative mastery of constrained circumstances occurred by optimising the goodness of fit between occupational form and occupational performance through adaptive capacity, an under-recognised form of agency in the context of chronic poverty. Looking beyond the obscuring façade of psychiatric disability at the ordinary things people did everyday revealed their capacity to strategise practically and attitudinally in support of the household's survival. The study heightens awareness of human experiences that have been overlooked in the occupational science and occupational therapy literature, in particular how the basics of occupation operate in resource constrained environments. This contribution to knowledge about human occupation will inform mental health occupational therapy practice and community based psychiatric services concerned with the inclusion of disabled people in promoting social development.

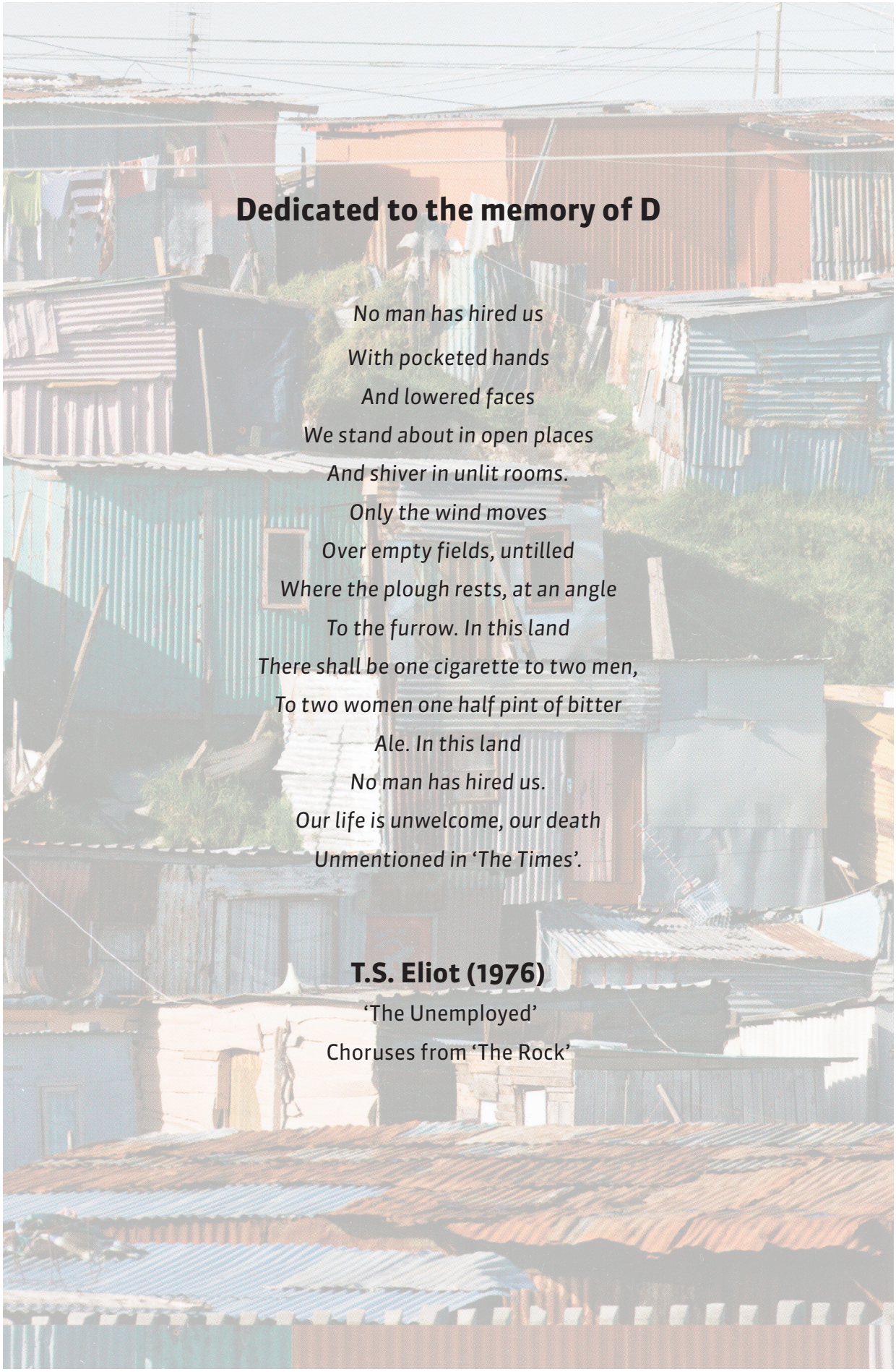
OPSOMMING

Hierdie studie val binne die gebied van arbeidsterapie en 'occupational science'. Dit beskryf die 'occupations' van Xhosa-sprekende individue met 'n geskiedenis van geestesongesteldheid wat in kroniese armoede in informele nedersettings aan die buitewyke van Kaapstad, Suid-Afrika woon. 'Occupation' verwys na die daaglikse take en doelgerigte aktiwiteite wat mense se tyd in beslag neem; die patrone en ritmes van hul lewens bevestig en wat uitdrukking gee aan hul verskeie rolle, identiteit, belangstellings en vermoëns. Die doel van die studie was om inligting te verkry oor die oorsprong, eienskappe, betekenis en funksies van 'occupation' in die konteks van armoede en veral met betrekking tot die psigiatries gestremde lid se belewenis en bydrae tot die huishouding se oorlewing deur sy of haar self-geidentifiseerde, primêre winsgewende 'occupation'.

Verlengde verbintenis met vyf huishoudings en sleutel informante as gevalstudies het die verkryging van kwalitatiewe data oor 'occupation' deur onderhoude, waarneming en fokusgroepe moontlik gemaak. Onderhoude met geestesgesondheidspesialiste vertroud met die konteks en die Xhosakultuur is ook gevoer. Vier tipes data-analise en interpretasie (Kavale, 1996; Stake, 1995) is toegepas om die ontwikkeling van substantiewe gevallestudies moontlik te maak: kondensasie (identifisering en organisasie van belangrike idees); kategorisering (tematiese sorteering van eenhede van betekenis); motief (narratiewe strukturering) en veralgemening (naturalistiese interpretasie). Kruisgevalanalise is toegepas om inligting oor die finansiële en sosiale kostes van 'n psigiatriese stoornis in die konteks van armoede te bekom asook die 'occupational' strategieë waarvan informante in die hantering van hul omstandighede gebruik gemaak het.

Die slotsom van hierdie verhandeling is dat psigiatries gestremde persone wat in die konteks van kroniese armoede 'n bestaan probeer voer, op paradoksale maniere 'n bydrae tot die voortbestaan van hul huishoudings lewer. Terwyl hulle siektegedrag die kwesbaarheid van die huishouding van tyd tot tyd laat toeneem, maak hulle nieteenstaande die oorlewing van die huishouding moontlik deur 'n kombinasie van die volgende bydraes: die verskaffing van bykomende arbeid; die beskikbaarstelling van 'n ongeskiktheidstoelaag en die produktiewe uitvoering van winsgewende 'occupations' in die sogenaamde 'tweede' of informele ekonomie. Die individuele, die sosiale en die strukturele is aan mekaar verbonde en beinvloed sodanig wat arm en gestremde mense daagliks in staat is om te doen. Hoe minder materiele komponente en hulpbronne in die 'occupational form' beskikbaar is, hoe groter is die inspanning wat benodig word om 'occupation' uit te voer en hoe meer afhanklik word die gestremde persoon op die informele sosiale ekonomie. Die teenoorgestelde is ook waar. Die

kapasiteit vir aanpasbaarheid, ‘n miskende vorm van agentskap in die konteks van kroniese armoede, maak die bemeestering van beperkte omstandighede moontlik. Die kapasiteit vir aanpasbaarheid is geleë in die vermoë om strategies, prakties en sielkundig te funksioneer. Die studie vergroot die bewustheid van menslike ervarings wat oor die hoof gesien is in die arbeidsterapie en ‘occupational science’ literatuur, veral hoe die basiese beginsels van ‘occupation’ funksioneer in omgewings wat gekenmerk word deur deprivasie en beperkte materiële besittings. Hierdie bydrae tot kennis oor ‘occupation’ sal arbeidsterapiepraktyk en gemeenskaps-gebaseerde psigiatriese dienste toelig asook die insluiting van psigiatries gestremde persone in maatskaplike ontwikkeling bevorder.



Dedicated to the memory of D

No man has hired us
With pocketed hands
And lowered faces
We stand about in open places
And shiver in unlit rooms.
Only the wind moves
Over empty fields, untilled
Where the plough rests, at an angle
To the furrow. In this land
There shall be one cigarette to two men,
To two women one half pint of bitter
Ale. In this land
No man has hired us.
Our life is unwelcome, our death
Unmentioned in 'The Times'.

T.S. Eliot (1976)
'The Unemployed'
Choruses from 'The Rock'

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1 All registers that may identify participants have been removed by using pseudonyms

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CHAPTER 1: INTRODUCTION

1.1 BACKGROUND TO THE STUDY

The broad subject matter of this descriptive study is the occupations[1] of five isiXhosa-speaking individuals with severe mental illness[2] living in chronic poverty[3] in an informal settlement on the outskirts of Cape Town. There has been little investigation in the fields of occupational therapy and occupational science into of the features of human occupation in the context of chronic poverty and psychiatric disability[4]. Occupational therapy is a profession committed to promoting health and well being by enabling people to participate successfully in their activities of everyday life. Occupational therapists achieve this outcome by addressing people's occupational performance or by modifying their lived environments to promote participation (World Federation of Occupational Therapy, 2004)[5]. Occupational science is a multidisciplinary research discipline created by occupational therapy pioneers in North America in the 1980's to study humans as occupational beings (Clark, Parham & Carlson et.al 1991; Wilcock, 2003; Yerxa, Clark & Frank et al, 1990). As a relatively new and evolving discipline, it values the importance and meaning of occupation in human existence and seeks to develop theoretical substantiations for occupation as the core focus of occupational therapy (van Niekerk, 2005). Situated at the interface between occupational therapy and occupational science, the central task of this dissertation is to promote understanding of

1 Occupation refers to the ordinary things that people do everyday and the way they expend their time, energy, interests and skills in meeting their needs (Christiansen & Townsend, 2004a).

2 A mental illness refers to an impairment of one or more areas of functioning with regard to social behaviour, rational thinking, feeling or judgement (State Library of Queensland Website, 2005). A mental illness may be considered severe when the disorder has lasted or is likely to last for more than 12 months. A chronically mentally ill person is someone who has a "severe and persisting emotional disorder that interferes with their functional capacities in relation to such primary aspects of daily life such as self care, interpersonal relationships and work or school" (Kaplan & Sadock, 1989, p.2090).

3 The chronically poor are people who experience poverty for extended periods of time or throughout their entire lives, whose children are also likely to remain poor, and who have benefited least or are likely to benefit least from economic growth and national and international development initiatives (Chronic Poverty Research Centre, 2004).

4 Psychiatric disability is a sociopolitical phenomenon experienced at an individual level as exclusion, stigmatization and restricted opportunities. It is caused by a prejudiced society that takes little or no account of people who, as a result of mental illness, have impairments of social behaviour, rational thinking, feeling or judgement (adapted from State Library of Queensland Website, 2005).

5 The profession's philosophical base is holism and humanism. Situated in the health and human sciences, its constructs tend to be normative and teleological.

the costs associated with psychiatric disability in chronically poor households[6]; the general strategies used by such households including the mentally ill person in dealing with their circumstances through the everyday things that they do and in particular, the contribution that mentally ill people make in promoting the economic survival of their households either through the strategic use of their disability grant or through the occupations that they pursue to generate augmentative incomes. The report will argue that psychiatrically disabled people are active, adaptive agents who, despite the risks that their illness behaviour and disability pose for the asset base of their household, nevertheless make a contribution to its livelihood.

South African occupational therapy has until recently[7] been moulded on literature and practice paradigms originating in Britain, North America and Canada. Literature emanating in these developed countries is based on assumptions that the average service user lives in a well resourced environment in which s/he has access to opportunities for self actualisation and for exercising choice in 'doing', 'being' and 'becoming' what s/he desires (Wilcock, 1998c, 2002). The 'good life' in the developed world does not necessarily align with the lives of people in the majority, developing world where the ideals of self-actualisation are clouded by the demands of daily survival in conditions characterised by marginalisation, exclusion and deprivation[8]. Hasselkus (2002), in discussing the meaning of occupation, reports that several graduate students in a seminar that she was conducting at an American university found Wilcock's (1998a) idea that occupation was potentially 'good or bad' unpalatable[9]. Hasselkus states that "they wanted occupation to be, by definition, only that which leads to healthful outcomes" (*ibid,* p.95). This view of occupation is understandable given the normative basis

6 Ellis (2000a, p.18), writing within the sustainable livelihoods framework, defines household as "the social group which resides in the same place, shares the same meals and makes joint or coordinated decisions over resource allocation and income pooling". MacGregor (2002, p.8), writing from an anthropological perspective, suggests that a household is emically constituted as an aggregation of individuals who share a common interest in insuring their mutual future security around a set of resources and potentials to generate income they believe they share. Commonly (although not necessarily), these individuals are linked through consanguine and affinal ties.

7 South African authors such as Watson and Swartz (2004) and Crouch and Alers (2005) describe contextually informed practice alternatives.

8 Marginalisation refers to the experience of being bypassed by most economic, political and social activity and therefore having precarious livelihoods (Department for International Development, 2001). Exclusion is the process through which individuals or groups are wholly or partially excluded from full participation in the society in which they live (European Foundation for the Improvement of Working and Living Conditions, 1995, p.4). Deprivation refers to a lack of welfare, often understood in terms of material goods and resources, but equally applicable to psychological factors, relative to the local community or the wider society or nation to which an individual, family or group belongs (Graaff, 2001, p.69). Wilcock (1998a) introduced the notion of occupational deprivation which she defined as being restricted, kept or hindered from acquiring, using or enjoying innate capacities, interests and skills. This construct is discussed again in Chapter 2.

9 Wilcock (1998a) argues that occupation in and of itself is value neutral. Its impact on individual health and well being occurs as a result of the motives (meaning) and goals (purposes) underpinning occupational performance with due consideration of the contextual factors influencing opportunity and choice.

of occupational therapy practice and its teleological interpretation of human functioning. It also confirms the need for information about occupations in contexts that compromise health and well being such as those characterized by chronic poverty.

Poverty, disability and occupation are complex, multidimensional constructs that are difficult to measure in terms of causal relationships. Their influences on one another, as they play out in individual lives, can however be described and understood through interpretation of experience. This study was based on the following three assumptions:

- Humans have an inbuilt need to be occupied. Occupation enables people to meet and obtain the requirements for living, health and well-being (Wilcock, 1998a). It was assumed that psychiatric disability would affect this inbuilt need in various ways depending on a range of internal and external mediating circumstances operating in the lives of individual participants including their personal, health and sociocultural histories.
- What people do as occupational beings is affected by their life experiences and the opportunities and choices available to them (Watson & Fourie, 2004). Occupational therapists and occupational scientists believe that 'doing' and 'being' are intimately linked to what people are able to become. While it was assumed that resource constrained environments would place particular kinds of restrictions on the choices and opportunities available to people; it was also assumed that these same environments would shape the expression of human agency in particular ways[10].
- As occupational beings, humans use their skills, agency, capacities and resources to adapt to and gain mastery over their world including being economically active (Watson, 2005; Yerxa, Clark, Frank et. al., 1990). It was assumed that psychiatrically disabled participants, given particular opportunities and resources, would make a contribution to the financial needs of their households. However, chronic poverty and psychiatric disability would impose particular forms of deprivation that would limit the realisation of their potential as actors in and on their lifeworld.

These assumptions point to occupation as one possible lens through which to examine the

10 Being refers to experiencing our existence, nature and constitution through the things we do and therefore becoming renewed or reduced. Doing refers to the actual engagement in occupation, experienced as embodied action or mindful activity unfolding through time (adapted from Hocking , 2000a, p.148 and Wilcock, 1998c). Becoming refers to an ever-incomplete process of something (may be perceived as a negative or positive difference or change) within a person coming into being (adapted from Wilcock, 1998c & Wilcock, 2006, p 148).
Agency refers to the 'capacity of intention…that is, motivational through rational thought, free will, motivation or emotions are able to direct their behaviour or make particular choices (Hayes, 2004, p179)

ordinary things that psychiatrically disabled people living in poverty do every day in meeting their needs. This dissertation is based on a sub-study within a larger, ongoing study into the dynamics between poverty, disability and occupation (PDO). The larger PDO study comprises five phases of which only Phase 1 has been documented (Watson, 2005). Phase 1 gathered descriptive, quantitative data about 32 households who met the PDO study inclusion criteria (discussed in Chapter 3). Based on snowball sampling, a demographic survey was conducted with the 32 households using semi-structured interviews and focus groups. Phase 2, the basis of this dissertation, commenced in 2004 and involved prolonged engagement with five households who were purposively selected from amongst the larger PDO study sample. Participants were interviewed and their participation in selected occupations was observed over a four year period. Phase 3 must still be implemented. It will investigate the interface between physical disability, poverty and occupation in a small sample of households also selected from amongst the Phase 1 sample. Phase 4 will involve an integration of the findings from Phases 1, 2 and 3. Phase 5, which commenced in 2007, is currently replicating the peri-urban PDO study in the rural Eastern Cape[11] with the aim of contrasting and comparing the impact of the structural and temporal environment on PDO dynamics. To appreciate the need for deeper professional understanding about PDO dynamics, the next section highlights pertinent socioeconomic features of the South African context.

1.2 THE SOUTH AFRICAN CONTEXT

South Africa has a population of approximately 47 million people (StatsSA, 2008). It is described as a developing, middle-income country and significant economic and social progress has been achieved since the first democratic elections in 1994[12]. Between 1995 and 2003, the gross domestic product (GDP)[13] grew at an average of nearly 3% and significantly more South Africans had access to improved housing, basic health, sanitation, potable water and utility services. Despite these developments, poverty in South Africa remains widespread and politicised. It has racial, gender and spatial dimensions that are the direct result of apartheid policies. According to the Department of Social Development (2002), the majority of black

11 See Appendix 1a for a regional map.

12 South Africa is a constitutional democracy. It's Constitution, amongst the most progressive in the world, serves as the primary organising frame for justice, equality and protection of citizens. In assessing the state of the nation, Southall (2007) suggests that the current South African government, given the challenges of post apartheid redress, is not yet fully developmental. A developmental state is one "which works successfully to combine extensive social redistribution with high economic growth, thereby effectively tackling poverty, overcoming historic racial divides, and generally rendering the economy more dynamic, innovative, just and equitable" (*ibid*, 2007, p. 1).

13 Gross domestic (national) product refers to the total value of goods and services produced domestically by a nation during a year (Graaff, 2001, p. 68).

South Africans survive below any acceptable minimum poverty line[14]. Absolute or relative poverty lines are used for measuring different dimensions of poverty for example income, expenditure, and growth curves[15]. The Taylor Committee (2002) reported that 18 million South Africans (45% of the population) at that time lived on less than $2 a day (about R16). While some poverty alleviation has been achieved through increased rollout of social grants, social inequality remains a significant development challenge. South Africa has one of the most extreme disparities in income in the world with its Gini-coefficient[16] estimated at the time of the study to be between 0.59 and 0.64 (Padayachee, 2006, p. 4). In 2000, the poorest 40% of households, comprising 50.5% of the population, received 11% of the overall national income, while the richest 10% of households, comprising 7% of the population, received 40% of the national income (May, Woolard & Klasen, 2000). Many South Africans earn a living in the informal economy[17] that contributes between 7%-12% to South Africa's GDP (Hart, 2006).

Poverty is linked with unemployment[18], a complex phenomenon to quantify. In 2005 the unemployment rate for females was 15% higher than that for males (Serumaga-Zake, Kotze & Madsen, 2005). Although wages at the time of the study had on average increased in real terms, remuneration increases mostly benefited skilled workers, while wages for unskilled categories of workers decreased on average (Seekings, 2003). According to Patel (2005) the

14 At the time of the study measurements of poverty were based on international criteria of $1/ day at local purchasing power parity per adult per day. In South Africa the poverty line fell between R322 (lower-bound poverty line) and R593 (upper-bound povety line) in 2000 prices (Hoogeveen & Özler, 2006).

15 Absolute poverty refers to subsistence below minimum socially acceptable living conditions and requirements for physical well being (nutritional requirements in terms of amount of calories). It is generally based on a quantitative proxy indicator such as income or salary but sometimes taking into account a broader package of goods and services (Hulme, Moore & Shepherd, 2001). Relative poverty is defined in relation to the social norms and standard of living in a particular society. Relative poverty can therefore include the individual's ability to take part in activities that society values, even if they are not necessary for survival (Chronic Poverty Research Centre, 2004b). Relative poverty compares the lowest segment of a population with the upper segment, usually measured in income quintiles or deciles (Yaqub, 2003).

16 Gini co-efficient is an aggregate numerical measure of income inequality ranging from 0 (perfect equality) to 1 (perfect inequality) (Padayachee, 2006)

17 Informal economy (also referred to as second economy) refers to that part of the national economy that is unable to attain the rates of growth that would ultimately end its condition of underdevelopment. The second economy is populated by the unemployed and those unemployable in the formal sector as well as people unable to generate the savings that would enable their labour to reach the high rates of investment needed for economic development (Hart, 2006). The notion of a second economy has been contested (Devey, Skinner & Valodia, 2005). This is briefly discussed in Chapter 2.

18 A suite of labour market indicators are used to describe unemployment including time related under-employment, underutilised labour and discouraged employment seekers (StatSA, 2008). Different criteria are used for different features of unemployment for example, Aliber (2003, p.478) refers to a person as being unemployed if s/he has actively sought but not found work in the past four weeks.

number of unemployed people in South Africa is increasing as is dependence on social security[19]. Public health services are only available to people receiving pensions and those whose low income complies with various means tests. If public service health care professionals in South Africa such as occupational therapists are to be contextually relevant in theory and practice, then they must take cognisance of the needs of this sector of the population; especially in terms of health promotion and the prevention of disability (Watson & Swartz, 2004).

The 2001 census estimated that more than 5.5% of the total South African population (estimated 2 255 000 people) had moderate to severe disabilities[20]. Access to social security[21] is important for poverty alleviation, ensuring a minimum standard of living and for achieving a more equitable income distribution in society (Patel, 2005). The disability grant[22] is the second largest social assistance programme in Rand terms. Between 2000 and 2003, the number of disability grants issued increased by 57%. About 3.5% of the population between 17 and 66 years received a disability grant in 2003 and by November 2004 there were 1,292,426 beneficiaries (Patel, 2005, p. 130). This growth is attributed to the rising number of people who are disabled as a result of HIV and the number of so-called able-bodied work seekers who cannot find employment. Despite the provision of equal opportunity for all workers, employers continue to favour the fittest workers making it difficult for disabled people to secure jobs (Seirlis & Swartz, 2006). Eligibility for a disability grant is determined by a number of factors, one of the most important being the person's inability to gain employment due to the presence of an enduring health condition or impairment. The reviewed period for a disability grant varies according to the type of impairment or health condition, whereas

19 Social security refers to a wide range of public and private measures that provide cash or in kind benefits or both, first, in the event of an individual's earning power permanently ceasing, being interrupted, never developing, or being exercised only at unacceptable social cost and when such person is unable to avoid poverty, and secondly, in order to maintain children. The domain of social security is: poverty prevention, poverty alleviation, social compensation and income distribution (Patel, 2005, p.123).

20 Disability is a form of social inequality or disadvantage resulting from oppressive social structures and processes rather than from individual difference or biology (Priestley, 2006, p 23).

21 The South African government pays out six state grants: care dependency, child support, foster care, disability grant, war veterans and old age pension. Social safety nets such as micro-credit, extended public works and social insurance programmes such as government saving and pension schemes are also available (Mitra, 2005). At the time of the study in 2004 temporary social relief (R700 for 3 months; +/- $70) was also available for destitute households.The total annual expenditure on grants in South Africa stood around R20 billion for 2002-3 or almost 9% of the non-interest government budget (Aliber, 2003). Taking into account subsidised healthcare and school feeding schemes, the government safety net at the time of the study between 2004-2008 was is in the order of R40-R50 billion per year.

22 A South African adult (aged 18-65) who is unable to work because of a mental or physical disability is eligible to receive a monthly payment from the Government (R970 in 2008). The disability grant, issued following a medical assessment and means test, is not given to anyone imprisoned, living in a state institution, a psychiatric hospital or receiving care from a state treatment centre (www.southafrica.info/essinfo/saglance/socialdelivery/securityagency. Accessed 6 November, 2008).

a care dependency grant[23] and an old age pension are given in the first instance until the child reaches the age of 18 years, and for the elderly, for as long as they live (from age 60 years for women and 65 years for men). While social grants play a pivotal role in poverty alleviation, they also pave the way for people to continue engagement in a range of valued life occupations that contribute to human development and social change (Lorenzo, 2005; Watermeyer, Swartz, Lorenzo et al 2006).

1.3 THE STUDY CONTEXT: KHAYELITSHA

Khayelitsha, a Xhosa word meaning 'our new home', is an informal settlement in a dusty, infertile and windswept area about forty kilometres to the south east of Cape Town[24]. It began to develop in 1983 when people fleeing the civil unrest and violence[25] in the nearby suburb of Crossroads, set up informal dwellings in vacant, unserviced plots of land. Spread out over approximately 30 square kilometres, Khayelitsha was home to approximately half a million people at the time of the study; 42% of the population were children with 18% of these being under 6 years old, 13% were aged 7-11 years and 11% were between 12-16 years old. According to a report by the City of Tygerberg (1997, p. 2), a "disregard for people's living environments in the past, inadequate service levels, and unregulated development, mostly as a result of demand for well-located private space in excess of supply, are found, notably in the west of Khayelitsha. This has resulted in degradation of sensitive ecological systems, illegal occupation of land, overcrowding of certain areas and functional under-utilisation of these areas by the community for recreational and traditional purposes". Sprawling and bustling, Khayelitsha is a hive of informal and formal businesses which are run from or amongst dwellings and in commercial zones. The municipal infrastructure (for example electricity boxes; running water on tap and toilets in homes) is underdeveloped. While steady progress is being made, the backlog in government built housing remains a major challenge.

In 1996 the magisterial district of Mitchell's Plain (MP) which includes Khayelitsha, accounted for 30% of the population of the Cape metropolitan area. When the study commenced in 2004, 74% of the population resident in the MP district lived in sub-districts such as Gugulethu, Khayelitsha, Langa and Nyanga (City of Tygerberg, 1997). The greater Khayelitsha municipality

23 Care dependency grants are paid to family members who look after a disabled child. The number of beneficiaries of this grant increased fivefold between 1998 and 2003.

24 See Appendix 1b for a map of the Cape metropolitan area.

25 For example, people were being "necklaced" – burnt to death by having a tyre soaked in petrol placed around the neck. It is believed that the unrest was deliberately instigated by factions within the apartheid government who did not want people settling in the area.

is divided into a number of health districts and suburbs (32 in total). Accurate information about the employment status of people living in greater Khayelitsha is fairly consistent across different surveys. A household livelihood study by the Cape Town Urban Poor in 2002 reported that 33% of households represented had an income of less that R100 per month per household member. According to Seekings (2003), 41% of people in Khayelitsha belonged to a marginal working class consisting mostly of informal traders. Levels of unemployment differed depending on area, but rose as high as 43% with no apparent differences between formal and informal housing areas.

The people living in Khayelitsha are predominantly isiXhosa-speaking. The Xhosa people are a group of clans within the Nguni, Bantu-speaking people in Southern Africa whose primary territory is situated in the Eastern Cape stretching from the Umzimkulu River in the north to the Great Fish River in the south[26] . Xhosa-speakers are divided into the Mfengu, Thembu, Mpondo, Mpondomise, Bhaca and Bomvana sub-clans identified by territory, history, dialect, cultural practices and patrilineage (Vivian, 2008). A hierarchical system of kin networks and chiefdoms hold authority while forefathers as ancestors guide traditions, cultural practices and marriage customs. Although people from the study areas continue to migrate to their rural homes in the Eastern Cape, more fluid notions of Xhosa identity are evident in urban communities (Vivian, 2008). Lasting relationships exist 'through blood' because of the patrilineal nature of clan membership. Children are seen to belong to all members of the older lineage and may be circulated amongst relatives while the children are growing up. The mobility of children amongst relatives applied in each of the households included in this study. The complexity of isiXhosa social networks, clan systems and cultural practices also formed the backdrop against which study participants described their occupations and health and poverty experiences[27].

1.4 THE STUDY RATIONALE

The paucity of information about the occupations of chronically poor and psychiatrically disabled people in South Africa raises the question: what would comprise an appropriate occupational therapy service for these and other similar cases? We will only be able to

26 See Appendix 1a.

27 See Appendix 2 for an orthography of the common isiXhosa words that featured in participants explanations of their experiences of psychiatric disability and poverty. These words were collated by the research assistants doing the interview transcriptions and by one of the research participants who kept a diary during the research period of his occupations and the cultural beliefs supporting what he did every day.

answer this question over time as the profession builds a body of knowledge pertinent to the context in which the majority of people needing public mental health services live. With the development of contextually relevant occupational therapy practice in mind, I suggest two reasons why learning more about occupation in the context of chronic poverty and psychiatric disability will benefit the profession in South Africa and contribute to the body of knowledge in occupational science in general.

Firstly, knowing more about human occupation in the context of chronic poverty can help occupational therapists understand the potential contribution of psychiatrically disabled people to the survival of their households. This information can direct the focus of occupational therapy intervention in hospitals; community based psychosocial rehabilitation services and social development projects.

Miller (2006, p. 461), discussing the global burden of mental illness[28] reports that, according to the World Health Organisation, "the majority of the world's 450 million people who suffer from neuropsychiatric disorders live in developing countries and that fewer than 10% of these people have access to treatment". Irrespective of where it is that occupational therapists work in South Africa, they are likely, given this statistic, to encounter people who have a mental health concern. Lund, Kleintjies, Campbell-Hall, Mjadu et al. (2008), in a five country mental health and poverty policy survey, identified occupational therapy as an important role player in the South African public mental health system contributing to community development programmes at the primary level of service. Occupational therapists are experts in promoting goodness of fit between individual capacities and needs and the demands of people's lived environments. Trained to work with individuals, they are also equipped to plan and implement occupation based comprehensive health programmes for groups of people (Crocu and Alers, 2005; Kronenberg, Simo-Algado and Pollard, 2005; Watson and Swartz, 2004). In short, while they are a valuable resource for promoting human and social development, occupational therapists currently do not have access to profession specific literature on human occupation in the context of poverty and disability.

Occupation, poverty and disability only have meaning in the contexts where they exist. In other words, individual experiences matter. Appadurai (2004), addressing poor people's capacity to aspire, notes that successful human and social development involves more than

28 Mental illness accounts for 12.3% of the global burden of disease and is estimated to rise to 15% by the year 2020 (World Health Organisation, 2001b).

redressing material deprivation. It means having a sense of agency, feeling that one can influence what affects one's life, that one has a voice, that one has the means to choose one's identity and that one has access to opportunities to realise one's potential through goal directed action. Since occupation is a means through which some of these aspirations may be realised, knowing more about what the nature of occupations are and how they are, or could be, effected in the context of chronic poverty and psychiatric disability, could inform occupational therapy interventions aimed at enabling, enriching and empowering people's involvement with materials, tools and other people (Christiansen and Townsend, 2004a). In short, occupation applied therapeutically and developmentally, can be the means for nurturing agency, promoting voice and supporting resilience in the context of poverty and disability.

Secondly, occupational therapy and occupational science debates will benefit from knowing more about how disabled people living in poverty negotiate and experience the structural barriers in their lived environments[29]*. This will enable practitioners to consider ways of working towards optimal contextual conditions that foster disabled people's participation*[30]*.*

Baingagan (cited in Miller, 2006, p. 461), a Ugandan psychiatrist advising the WHO on mental health issues, warns that many officials and policy makers do not have enough evidence to recommend investments in mental health services in poorer countries. She suggests that "... convincing sceptics will require demonstrating the economic costs of untreated illness more clearly and countering the persistent view that a person with a mental disorder will never function at a normal level ... [W]hen we show that people with neuropsychiatric disorders can be productive, then we will have greater interest ". Occupational therapists, as health practitioners concerned with people's occupational performance, are potentially in a position to contribute this kind of information[31]. Only disabled people themselves can however provide adequate and legitimate representation of their own interests. This means that occupational therapists must join forces with constituencies lobbying for the rights of psychiatrically

29 Environment refers to the attitudinal, systemic, legislative and physically built setting or context (World Health Organisation, 2001a).

30 Participation refers to engagement in chosen life pursuits in an environment in which physical and attitudinal barriers are managed structurally (adapted, adjusted, modified etc) so that inclusion and equal opportunities are possible (WHO, 2001a).

31 Occupational therapists have an established role in work preparation of injured workers, vocational rehabilitation and, increasingly, the economic empowerment of disabled people. However, the cost benefits of successful vocational rehabilitation and community based economic empowerment remains under researched and reported.

disabled people including poverty alleviation initiatives aligned with their needs[32].

According to Yeo and Moore (2003) where poverty is one aspect of a disabling society, disability is the other. The two states of existence interact to exacerbate chronic poverty. Disability issues are therefore important to all facets of development work including public mental health programmes (Lund, Kleintjies, Campbell-Hall, Mjadu et al, 2008). While there is a growing volume of research on poverty and mental illness (Lund, Kleintjies, Campbell-Hall, Mjadu et al, 2008; Lund, Breen, Flisher, Swartz et al., 2007), studies on the intersections between chronic poverty and psychiatric disability are rare. A search through international development journals by Yeo and Moore (2003) for disability, impairment and related words yielded only 24 articles over the preceding five years. Medicalisation of disability was prominent with the focus being on health[33] rather than poverty or development issues. This was also the case in the occupational therapy literature reviewed for this report[34]. Yeo and Moore (2003) suggest that the dearth of scholarship on disability and poverty is the cause and effect of exclusion and marginalisation of poor and of disabled people and that research is hampered by lack of consensus about what disability and poverty is.

The 'invisibility' of psychiatric disability makes the marginalisation of people with mental illness particularly problematic in development work. Devereux (2002, cited in Mitra, 2005, p. 6) states that persons with disabilities "survive by being cared for within their families or communities by institutional redistribution from the state (funded by taxes bid by the economically active) or by charity and begging which is a form of work … disabled people are not expected to participate in livelihood programs yet benefit from cash transfers". While this is true in terms of the fiscal burden of social security payouts, it is completely contradictory

32 Metts (2002) argues that since there is paucity of information on disability in most developing countries that disability should, in consultation with disability organisations, become a cross-cutting theme in all poverty reduction work and research. If disability is treated solely as a specialist issue and not included in policy formation or development strategies, the exclusion and poverty faced by (psychiatrically) disabled people will not be addressed (Lund, Kleintjies, Campbell-Hall, Mjadu et al, 2008). Their potential contribution to society and the economy will neither be appreciated nor tapped if the focus is primarily on the provision of social security. Focussing on the economic inclusion and social participation of disabled people will promote the development agenda.

33 In this instance health refers to a state of complete physical, mental and social well - being and not merely the absence of disease or infirmity (World Health Organisation, 2001a).

34 An extensive electronic search yielded no evidence-based studies. A review of five international occupational therapy journals over the past three years and a number of textbooks yielded no articles focussing specifically on the interface between poverty, psychiatric disability and occupation. Poverty was only mentioned as a confounding factor in occupational performance while disability received substantial coverage in terms of occupational therapy intervention (Kronenberg, Simo-Algado and Pollard, 2005). One South African doctoral study on disability, poverty, human development and social change was located (Lorenzo, 2005). This in no way claims to be an exhaustive literature search but it indicates lack of prevailing thinking on the subject in the occupational therapy and occupational science literature.

to the perspectives of disabled people themselves about their rights to and capabilities of economic inclusion in society (Lund, Kleintjies, Campbell-Hall, Mjadu et al, 2008; Seirlis & Swartz, 2006; Oliver, 1996; van Niekerk, 2006). Narrow medicalised conceptualisations of disability demonstrate little appreciation of the personal and economic costs associated with marginalisation. Nor do such conceptions affirm the rights of disabled people to be included as equal, productive citizens. Exclusion of their knowledge and blocking their participation is tantamount to the inefficient use of human resources ultimately contributing to the entrenchment of poverty (Yeo and Moore, 2003).

Structural poverty[35] in particular creates a disabling environment that traps poor people in living conditions characterised by marginalisation and deprivation. The political agenda of occupational justice[36] is focussed on humans as occupational beings who, structurally marginalised by their position in society and by their lack of access to social power and resources, are denied the fundamental human right to meet their innate need for meaningful and purposeful occupation (Townsend & Wilcock, 2004b). The broad implication of structural poverty seen through the perspective of occupational justice is that "in health, community services, employment support, housing, school, transportation, corrections, higher education, private business and other systems worldwide, occupational therapists can choose to either advocate consciously with others for justice, or comply with occupational injustices through silence and inaction" (Townsend & Wilcock, 2004b, p. 83). The challenge of occupational therapy and occupational science research and practice is therefore to encode ideas about rights, needs and privileges as these pertain to what (disabled) people living in chronic poverty are able to do everyday, ie. their occupations. A focus on human occupation in a structurally adverse context may offer some insights towards this agenda. In short, people are occupational beings in a particular context and unless we know more about the context, we will not be able to address the barriers that exclude people from participation in society[37].

1.5 PROBLEM STATEMENT OF STUDY

There is currently very little information in the occupational therapy and occupational science literature about the occupations of chronically poor and psychiatrically disabled people living

35 Structural poverty refers to the situation of people whose advancement is blocked by patterns of power and discrimination in society (Graaff, 2001, p 69).

36 Occupational justice is concerned with the recognition of and provision for the occupational needs of individuals and communities, as part of a fair and empowering society (Wilcock & Townsend, 2000, p.84).

37 Disabled people who receive social security are often in a better off position than their neighbours in poor communities who do not have a regular income. The point here is that chronic poverty adversely affects everyone involved including disabled people.

in adverse socio-economic environments. In particular, little is known about what occupation involves ie. what it takes for mentally ill people living in chronic poverty to do the everyday things that they need and want to do and how their occupational performance affects the household's livelihood.

1.6 PURPOSE OF THE STUDY

The purpose of this study was to obtain information about the occupational performance of psychiatrically disabled people living in chronic poverty. Knowing more about what chronically poor people do to help themselves and about the impact of psychiatric disability on the asset base of poor households will help to guide the focus of occupational therapy mental health services in developing contexts and advance theory development in occupational science about the construct of occupation.

1.7 AIM AND OBJECTIVES OF THE STUDY

The aim of this study was to describe how poor households and persons with psychiatric disability living in those households coped with their circumstances and how they viewed, orchestrated, drew meaning from and attributed purpose to the everyday things they did, in particular the self-identified, primary income generating occupation of the disabled person.

The study objectives were to:

- profile the psychiatrically disabled informants in the context of their household structures with reference to their occupational and health history
- describe the costs of psychiatric disability to poor households
- identify the strategies within everyday occupations that were used by the disabled person and his/her household to deal with poverty and psychiatric disability
- analyse the primary income generating occupation(s) of the psychiatrically disabled person with reference to the following basic features[38]:
    - occupational form
    - the developmental structure of participant(s)
    - meaning and purpose
    - occupational performance

38 The basics of an occupation represented here are based on the work of Nelson and Jepson-Thomas (2003, p.111) and discussed in Chapter 2 (see page 21). This conceptual frame was adopted to guide data gathering, analysis, interpretation and reporting because it was considered to be the most relevant, useful and current one available in the occupational science literature.

1.8 RESEARCH QUESTIONS

The following set of questions shaped the iterative formulation of the interview guides[39]:

- What is the personal, environmental and occupational asset base of the index person and his/her household?
- What patterns of occupations are evident in the index participant's lifestyle and health behaviours that impede or facilitate the functioning of this household?
- What meanings and purposes are ascribed to the occupations (or lack of occupation) that the index person participates in?
- How is the index participant's occupational engagements affected by their geo-socio-political location?
- In what ways are occupations in this household created, learned, shared and why?

1.9 CONCLUSION

Framing the background to the study, this chapter has provided a description of the study locality, detailed its rationale and circumscribed the study problem, purpose, aims and objectives. The discussion has drawn attention to the paucity of occupational therapy and occupational science research on the intersections of human occupation with chronic poverty and psychiatric disability and has presented the advantages of investigating the basics of occupation for professional scholarship. It has argued that occupational therapy practice in South Africa will be contextually relevant when it operates from a deeper appreciation of occupation; in particular those features of occupation that reflect individual resilience, aspiration and agency in the context of disabling health and restrictive social conditions. The rationale for this focus was argued in relation to occupational therapy mental health services and the contribution of the profession to social change through community based interventions. Chapter Two provides an overview of the occupation, poverty and psychiatric disability literature.

39 Chapter 3 point 3.3.7 and Appendix 6.

CHAPTER TWO: LITERATURE REVIEW

2.1 INTRODUCTION

Given the paucity of studies about human occupation in the context of chronic poverty and psychiatric disability, this chapter reviews literature that pertains to each of the three key constructs indicating links where these have been reported. Occupation has been extensively theorised in relation to its therapeutic application in occupational therapy[1]. It is still in the process of being theorised as a construct in the occupational science literature (for example, through the Journal of Occupational Science and the work of authors such as Christiansen and Townsend, 2004a; Hasselkus, 2002; Zemke and Clark, 1996). Occupation will, in this chapter, be discussed conceptually and not within a particular therapeutic theoretical framework. A therapeutic focus falls outside the domain of the study which, as indicated previously, is situated at the interface between occupational therapy and occupational science. An overview of the key features of occupation is presented before the basics of occupation including occupational form, process and mechanism are discussed. This is followed by a framework for categorising occupation. Extant social theories that have been used in the initiative to explain aspects of occupation are mentioned but not explicated. Approaches to and basic concepts in poverty are then briefly reviewed followed by an overview of literature addressing psychiatric disability, the links between poverty and mental illness and the role of belief systems in people's understanding of emotional distress and behavioural disorder. The chapter highlights the complexity of poverty, disability and occupation as individual constructs and suggests that their relation to each other is equally complex and analytically elusive.

2.2 OCCUPATION

Definitions of occupation tend to be expansive and inclusive making the construct difficult to circumscribe for research purposes and for formulating into succinct questions for research exploration. Being a phenomenon that unfolds and constantly changes in the stream of time, it is difficult to pin point where occupation starts and ends and even, how it is different from

1 Occupation is core to the profession of occupational therapy. Much has been written about the use of occupation as the means in therapy to bring about change in a person's functioning when it has been affected either by an inherited or acquired health condition. Occupation as end is the goal or outcome of intervention. Used in this manner, occupation involves participation in meaningful activities and tasks within the context of the person's life (Kramer, Hinojosa and Royeen, 2002). No studies could be traced that focused specifically on the essential features of occupation outside the context of therapy in relation to the psychiatrically disabled occupational human living in chronic poverty.

human behaviour in general[2]. It is therefore helpful to bracket occupation with reference to its core elements yet much controversy exists about exactly what these are[3]. Defined succinctly, occupation is "the ordinary and familiar things that people do everyday" (Christiansen, Clarke, Kielhofner et al., 1995, p. 1015). The things that occupy people's time can be named in the lexicon of their culture and enable them to "use and even seize control of time and space (or place)" (Christiansen & Townsend, 2004a, p. 2). Everyone understands what you doing when you say you are mowing the lawn, bathing a baby, baking bread or digging a trench, provided of course that these are ordinary and familiar things that are done within the group or society that you are part of. As recognisable life endeavours, occupations provide structure and routine to daily life. They enable people to meet their various needs as well as give expression to their individuality, interests and abilities. Yerxa (1993, p. 3) suggests that the study of occupation pursues "...the widest and deepest questions concerning human beings as actors who adapt to the challenges of their environments via the use of skill and capacities organized or categorized as occupation"[4]. Controversy however exists about how these skills and capacities are organised and categorised, in particular the distinction between occupation, activity and task. This is briefly addressed in the following section because of its implications for the study methodology.

2.2.1 Occupation, activity and task

The distinctions and similarities between the constructs of occupation, activity and task in the occupational therapy and occupational science literature has been widely discussed with some contention (Golledge, 1998; Kramer, Hinojosa & Royeen, 2003; Polatajko, Davis, Hobson et al, 2004). Some argue for a ban on the term 'activity', calling instead for the exclusive use of the term occupation with its components being referred to as 'sub-occupations'. Polatajko

2 Occupational therapy has its historical roots in holism; a systems philosophy that views individuals as integrated organisms in which the elements of mind, body, spirit, emotions, and environment interact. The living organism is a whole that is more than the sum of its parts. Holism believes that the interdependence of all these parts determines the nature of the entire organism's existence (Wilcock, 2006). This philosophical position has enabled therapists to adopt an individual-based, reductionistic orientation to human activity in health and disability while considering the whole person in context. The evolving discipline of occupational science is opening up vistas of occupation as self-action and inter-action; as the relational glue between the individual and the social (Aldrich, 2008; Cutchin, Aldrich, Baillard and Coppola, 2008). Here occupation potentially takes on gestalt as the means through which "humans and context exist in an ongoing process of reproduction and occasional transformation, dependent on one another for their current states of existence" (*ibid*, 2008, p162) i.e. occupation is a construct for appreciating the agency, actions and adaptive capacity of humans in and on their lived environments AND of the environment's effect on them.

3 The main critique being the lack of a coherent meta theory that explains human action (occupation) as both an individual and a social phenomenon (Aldrich, 2008)

4 Grounded in the human and health sciences, a number of taxonomies exist that detail the essential features, functions and purposes of occupation either as the means through which people engage with life or as the means through which intervention occurs (for example, Christiansen and Baum 2005; Canadian Occupational Therapy Association, 1997; Hagedorn, 2000;).

et. al. (2004) point out that while this is a radical solution for the language dilemma of defining exactly what occupation is and what its core elements are, it is also an unworkable one because it makes communication with clients, colleagues and the public very difficult. They argue that no one term "...be it function, work, activity, occupation, is enough for our profession to discuss and understand human occupation" (Polatajko et. al., 2004, p.261).

Various taxonomies have been developed to address this dilemma. General agreement is that activity is a sub-component of occupation, "describing brief units of human doing" (Nelson & Jepson-Thomas, 2003, p. 149). A task is "an objective set of behaviours necessary to accomplish a goal" (Dunn, Brown & Youngstrom, 2003, p. 226). Christiansen and Baum (2005) concur, seeing occupation as the composite of activities (for example reading an article and writing notes), tasks (for example studying for a test) and roles (for example being a student). Polatajko et al (2004) propose a seven level taxonomic framework for occupational performance ranging from voluntary movement as the lowest denominator, through movement patterns, action, task, activity and occupation to occupational grouping as the highest denominator. They argue that such a range is indicated because "our interest in human occupation addresses numerous levels ranging from movement at a single joint to integration into the workplace" (ibid, 2004, p.261).

While taxonomies are relevant for the purposes of circumscribing occupational therapy practice and research, they tend to essentialise[5] the complexity of human occupation. For example, the critical difference between activity as it is understood and analysed for therapeutic purposes in occupational therapy (Lamport, Coffey and Hersch, 2001) and other theories of human activity (for example Activity Theory[6]) is its focus on the biopsychosocial

5 Essentialism refers to the generation of "internal categories of personhood that are unchanging and timeless, that come to be inescapable, and that therefore bear a determining influence of sorts on the person in question" (Parker, 2004, p.140). Anti-essentialism is an approach to subjectivity which suggests that persons are not fixed, predetermined, immutable or unchanging essences (Hook, 2004, p.146).

6 Activity theorists see activity as "being at the explanatory core of human behaviour and subjectivity" and as "object-orientated action mediated by cultural signs and tools" (Van Vlaenderen & Neves, 2004, p. 432). Activity Theory "recognises the dialectical relationship between the individual and society. Rooted in the historical materialism of the (former) Soviet Union, it points at the manner in which historical and material conditions of existence shape psychological functions (eg. thinking and problem solving). Activity Theory eschews all forms of determinism, including the view that human functioning is wholly shaped by external factors. It focuses on mediation: the process by which human beings use cultural tools such as language and stories to carry out their actions" (Mkhize, 2004, p.416). Activity Theory therefore stands apart from the way in which activity is understood in occupational therapy and in particular in the disability literature where activity is linked to body function and structure(WHO, 2001a).

developmental structure[7] of the individual actor in a particular field of action. This normative focus, originating from the profession's biomedical roots, is both a strength and a weakness. On the one hand, analysis of an activity enables the therapist to achieve goodness of fit between an individual's health (and other) needs, abilities and the demands of the activity with due consideration of the action environment. It also enables an understanding of the developmental structure supporting an individual's performance in response to the demands of a particular context to emerge. On the other hand such a normative approach to activity, when transferred to thinking about occupation, limits an appreciation of occupation as a complex intra, inter and transpersonal process (Aldrich, 2008). It reduces occupation to a series of steps with limited consideration of context. Occupation is a dynamic phenomenon that engages people's abilities, energy and attention in constantly changing ways within and across the stream of time. A heuristic and systems approach, pervasive in occupational therapy practice and theory, characterises environment as a container of behaviour and in so doing, insufficiently addresses the interpenetrating nature of the real world where individual and social behaviour is transactionally co-constituted (Cutchin, 2004). Occupation, as a construct, operates not only at the interface between the individual, the social but also the structural. The point being made here is that the things poor and disabled people are able to do everyday is as much a function of their personal capabilities as it is of the social systems and the structural forces operating in the context of their lifeworld.

Cutchin, Aldrich, Baillard and Coppola (2008) argue that occupational scientists have not yet produced sufficient analyses of action theories as a potential basis for understanding occupation. They review the theoretical contributions of John Dewey and Pierre Bourdieu

7 Developmental structure consists of sensorimotor, cognitive and psychosocial abilities and characteristics. The term "developmental" implies that the structure is the end product of a long-term process influenced by maturation (genetically unfolding physical change) and past occupational adaptations (personal experiences) (Nelson & Jepsen-Thomas, 2003, p.99)

as a basis for understanding how habit[8], context[9] and creativity[10] operate in human action and by extension, human occupation. Cutchin et. al. (2008, p.164) define occupation as a "type of relational action through which habit, context and creativity are co-ordinated toward a provisional yet particular meaningful outcome that is always in process; the type of occupation is defined by the particular combination of habit, context, creativity, and provisional outcome". This definition sees "occupations as forms of action in which independent notions of structure and agency melts away. What takes their place is a form of relational action composed of habit and creativity (from personal and social sources) and the social and environmental contexts through which they operate and which they reshape" (ibid, 2008, p.164). What we see here is closer alignment with extant meta theories on human action that allow the complex interface between the individual, the social and the structural to emerge in descriptions of human occupation (Aldrich, 2008; Dickie, Cutchin and Humphry, 2006)[11].

Attempting to bring some coherence to debates at the time, Hocking (2000b) identified the following key elements of occupation that are commonly reflected within occupational science literature:

- it is culturally, temporally and ecologically contextualised;
- it has a purpose or goal which may or may not be aligned with cultural ideas about its purpose;
- it is subjectively experienced and is the product of human capabilities.

8 Habits have been variously understood in the profession ranging from reductionistic definitions that see habits as specific, individual, unconscious sequences of behaviour (Kielhofner, 2002) to complex understandings that see habits as "acquired system of generative schemes" developed during childhood and reinforced by sociopolitical environments" (Cutchins et al, 2008, p.159). By integrating these perspectives we come to appreciate that human action, and by extension human occupation, is "not only an individual process but also a social and political one" (Cutchins et al, 2008, p.160).

9 Context in occupational therapy and occupational science literature comprises physical, psychological, social, cultural, historical and temporal elements. These elements create particular forces and shaping circumstances on human occupation. Cutchins, et al.(2008, p.161) state that "human action is inseparable from the contextual foreground and background with which it occurs". The dialectical interaction between the individual and the contextual has profound implications for the impact of structural poverty and disability on what people do every day.

10 Creativity is a human phenomenon which involves bringing into being by force of imagination or forming, designing or making something into an alternative form. It suggests "exceptional human ability, inventiveness, originality and imagination" (Sadlo, 2004, p. 91). Linked to occupation in the literature, it is considered "a quality or capability that is present to varying degrees in all human beings and that potentially manifests itself in virtually all aspects of daily life" (Hasselkus, 2002, p.116). This raises questions about the links between creativity, imagination, motivation and agency in the context of disability and poverty. What happens to these human traits in disabling structural environments?

11 Examples are pragmatism (such as Bordieu's work on the individual in social space; social inequities and their impact on habit and action) and transactionalism (such as Dewey's work on the relational connection between the person and "environment-as-a whole").

In light of these identified elements, it could be argued that the literature sees occupation as fundamentally an individual human endeavour. Nelson and Jepson-Thomas (2003, p.127) state "there is not such a thing as a group occupation or a shared occupation. For each person involved, there is a different occupation. Two or more people can have reciprocal occupations in relation to each other". While each player on a soccer field is busy with his or her own occupation, certain common elements can however be identified such as the field of action, the rules of the game and the biopsychosocial demands it places on the player. According to Wilcock (2003, p. 9) occupations collectively demonstrate "a community's and an individual's culturally sanctioned intellectual, moral, social and physical attributes". What is being argued here is that we can learn something about people's abilities, beliefs and motives by observing them in their functional environments and by asking people to explain why and how they do what they do at particular points in time[12]. Occupation can, in short, be segmented for research purposes into recognisable attributes that are observed and discussed as a discrete life endeavour (Clark, Parham, Carlson, et. al., 1991; Nelson and Jepson-Thomas, 2003). Sometimes these attributes may be recognisable activities and tasks; sometimes they may be tacit processes but the whole, the construct of occupation, will always be more than the sum of its parts.

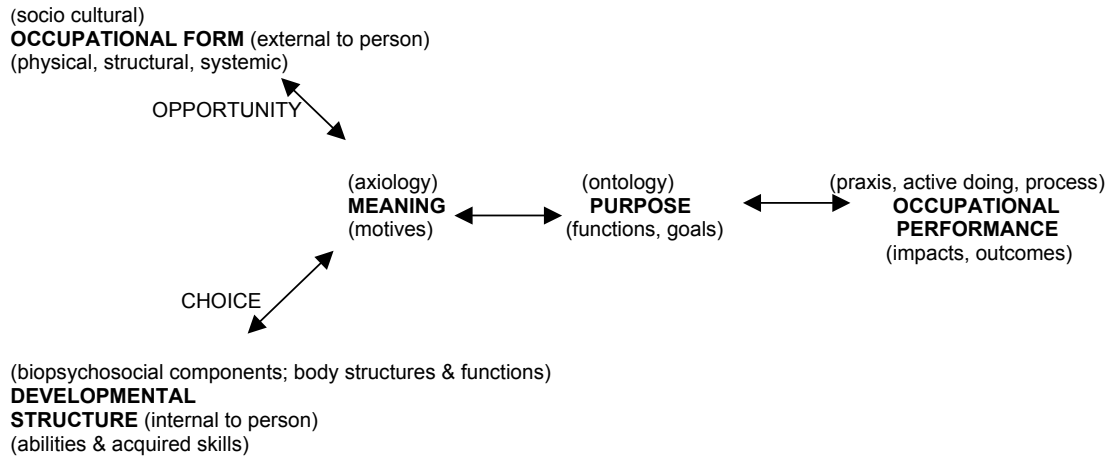
2.2.2 The basics of an occupation

A number of frameworks for understanding the basics of an occupation exist. The framework suggested by Nelson and Jepson-Thomas (2003) was selected as the primary conceptual tool for the purposes of this study. It is comprehensive in that it contains the possibility of reflecting the individual, the social and the structural while being easy to grasp and apply. Nelson and Jepson-Thomas's (2003, p.111) diagram of the basics of occupation has unidirectional arrows running from occupational form and developmental structure on the left through meaning and purpose to occupational performance on the right. I adapted this diagram by introducing bi-directional arrows believing that occupation is a reciprocal interaction between actor and form; each influences and is influenced by the other ie. the individual, the social and the structural intersect in human transactions (Cutchin, 2004; Cutchin et.al., 2008). Figure

12 Occupational therapy engages with people at this particular point i.e. at the interface between their abilities, interests and motives and the practical challenges of their daily lives that occur as a result of inherited, developmental or acquired impairments and the environments in which they need and want to participate. Moving beyond the medicalisation of disability, the profession also works developmentally with humans as occupational beings in their lived environments (Kronenberg, Simo-Algado and Pollard, 2005; Watson and Swartz, 2004). This dual perspective posed a methodological challenge for the study: understanding occupation in the context of chronic poverty and psychiatric disability meant balancing an essentialist knowledge of psychiatric impairment as it impacts on biopsychosocial human functioning with due consideration of the structural and systemic influences that shape human action and social behavior.

1 depicts the basic elements of an occupation, adapted from the work of Nelson and Jepson-Thomas (2003).

Figure 1: the basics of an occupation
(adapted from Nelson and Jepson-Thomas, 2003, p.111)



External to the person (actor, doer, occupational performer), **occupational form**[13] consists of tangible and intangible resources and influences on what can be (and is actually) done. Disability and poverty, as socio-political constructs, operate as features of the context within which occupation occurs. They influence the material configuration of the occupational form, creating opportunities (or not) for performance. Internal to the person, the **developmental structure**[14] serves as the means (mechanism, vehicle) through which s/he is able to make choices within or act on the demands of the occupational form. Using body functions and structures (which may or may not be impaired), the person draws on personal abilities and acquired skills to act on or respond to occupational form. **Meaning**[15] **and purpose**[16] are linked to the doer's values, beliefs, motives and goals while **occupational performance**[17] involves

13 Occupational form is the objective set of physical and sociocultural circumstances, external to the person, at a particular time. The form guides, structures or suggests what is to be done by the person (Nelson & Jepsen-Thomas, 2003, p.90).

14 Developmental structure: see footnote 7 above

15 Meaning involves perceptual, symbolic and affective interpretive experiences of encountering an occupational form (Nelson & Jepsen-Thomas, 2003, p.101). Meaning is axiological; it draws on and informs the person's values and is linked to "making-sense-of" everyday activities, tasks and roles in terms of their existential value.

16 Purpose is the felt experience of desiring an outcome (having a motive) (Nelson & Jepsen-Thomas, 2003, p.107). Purpose is ontological; it is concerned with the reason for doing something; the outcome or goal towards which action is directed.

17 Occupational performance refers to the active doing of the person in the context of the occupational form (Nelson & Jepsen-Thomas, 2003, p.111).

the praxis[18] between form, developmental structure, meaning and purpose ie. the actual doing for particular reasons by the person in the context of a particular occupational form. The components of the basics of occupation feature throughout this research report. The reader will be prompted to return to this section whenever indicated. The aim is to promote evidence of conceptual coherence in explicating, from the findings, the interaction between a very complex set of concepts within the construct of occupation. In the interest of brevity, features of occupation are now clarified using the research context as point of reference.

2.2.3 Occupational form and performance

Occupational form is the objective, pre-existing structure or environmental context that elicits, guides and influences human action either directly (the actor engages actively with form for example materials and tools used to make a meal) or indirectly (the form with which the actor is able to engage is shaped by systemic influences beyond his or her control for example, not having electricity may mean having to light a fire in order to cook a meal). Occupational form affords (or not) people access to the resources that they need in order to act on their world[19]. The interaction or process that occurs between the "doer" (a person with a unique developmental structure) and the occupational form is directed at a particular purpose[20], goal or outcome and is imbued with perceptual, symbolic and affective meaning[21] particular to the individual's personal, cultural and social history and life experiences (Nelson & Jepson-Thomas, 2003).

Occupational performance involves "voluntary doing by the person within the context of the occupational form", that is, the doer engages with form to produce a tangible or intangible outcome (Nelson, 1999, p.77)[22]. Things change internally/personally and externally/structurally

18 According to Wilcock (2003, p.161, citing Petrovic,1983) definitions of praxis range from "that which treats it simply as human activity through which man changes the world and himself, to more elaborate ones which introduce the notions of freedom, creativity, universality, history, the future, revolution etc". For the purposes of this study, praxis was viewed as the former ie. occupational performance involves the person acting on his or her lifeworld (lived space and place; material and non material reality) and in so doing, both that lifeworld and him/herself is changed.

19 People either have or do not have the resources necessary for action as a consequence of the form at their disposal. Having refers to accessing means such as tools, materials, money (tangible) as well as skills and capabilities (intangible) to do things and through having and using these means, knowing more of who we are and what we might do (become) (Hocking, 2000a, p.148). This description of 'having' implies that people who are restricted in 'having' (for example as a result of poverty or disability) may also be restricted in the kinds of self-knowledge required for action on the world ('doing') that leads to change and emancipation ('becoming').

20 Purpose involves having an intention or motive which may or may not be personally meaningful for the individual.

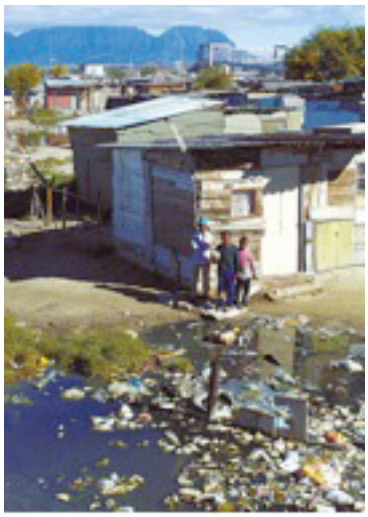
21 It is debateable if this feature of occupation is a universal experience.

22 It is debateable whether or not all occupational performance is voluntary.

when people act on their world. Performance leads to outcomes and impacts. People perform occupations without necessarily being aware of the reasons and motives behind the things that occupy their time, effort and energy[23]. Since occupation involves interpretation of the occupational form and is elicited by the unique developmental structure of the individual, different people will perform occupations in different ways and will attribute different meanings to the same occupational form[24]. The macro, meso and micro environment shapes what form occupation takes. Picture 1 depicts the physical environment of an informal dwelling as an example of occupational form that pertains to the interface between poverty and occupational performance.

Picture 1: Environment as occupational form: informal dwelling

While the health hazards in Picture 1[25] are obvious (for example lack of piped water, flush toilet and refuse removal services), the particular barriers to participation faced by disabled people such as terrain are often less considered[26]. Besides the characteristics of the immediate geophysical setting within which people function, the occupational form also includes the tangible goods, furniture, materials, tools and equipment needed for occupational performance. Sociocultural dimensions in the occupational form also affect the perceptions and interpretations of



23 Occupations may be habitual for example self care. These only become difficult when automatic actions become conscious as a result of impairment that restricts function for example the task of brushing teeth may pose a problem to someone with an upper limb paralysis or hand injury. It becomes a disability when aspects of the occupational form for example the toothbrush or toothpaste tube, are designed in ways that do not enable unilateral function.

24 For example some people like cooking because of the feelings associated with the preparation and presentation of food. For others the occupation holds little affective meaning, its purpose being simply to prepare food for sustenance. As mentioned previously, for some, the notion of meaning may in itself be a foreign concept when applied to the ordinary, everyday things that they do.

25 Source: http://www.library/thinkquest.org/28028/lintloko.html. Accessed, 25 March, 2009.

26 For example, wheelchairs have to be prescribed with due consideration of an individual user's anthropometric features and mobility needs. In addition to this, the environment in Picture 1 requires a very particular type of wheelchair, robust enough to traverse the rough terrain and compact enough to fit into the confined spaces inside informal dwellings and long drop toilets. A large consignment of wheelchairs was donated to the Eastern Cape rehabilitation programme by a philanthropic Japanese consortium. Much to the consternation of municipal officials, occupational therapists could allocate very few of the chairs because they were unsuited to the needs of people with mobility impairments and the type of occupational form where the intended population lived (Personal communication: OT, Mount Frere, 2007).

actions taken in a particular context[27]. The temporal features of occupations indicate that they extend over time, may be habituated, and help people adapt to and gain control over their physical environment. How the form of the occupation begins, how it is controlled and what is involved in the doing, points to occupation as active participation (Hocking, 2000b). The product(s), outputs or outcomes of occupation may be tangible or intangible.

People are able to discern (this may depend on whether an impairment[28] is present or not) when they are involved in an occupation because they know when, why and how they exert control over their performance; they recognise that it requires energy, interest, attention and motivation and that it involves the use of their body functions and structures[29]. The central argument being made here is that a transactional relationship exists between occupation, disability and poverty.

Picture 2: Occupational form involved with cooking sheep heads

Picture 2[30] depicts the occupational form involved with the occupation of cooking of sheep heads (called 'smileys'). Sheep heads are roasted on an open fire until the hair and skin can be scraped off. The head is then spliced open to access the meat. Various steps or tasks are involved in doing this form of occupation using different components of body function and structure and materials and tools. Aspects of the form can be objectively identified and systematically recorded such as sheep heads, boiling water, fire and various tools. Performing this occupation depends on access to an abattoir or

27 Context is defined as "a set of interrelated conditions that surround a person" (Dunn, Brown and Youngstrom, 2003, p. 224). Structural poverty shapes context at a systemic level. It determines the way people are positioned in society in terms of discursive forces such as power, class status and distributive justice. Temporal context includes aspects of chronological age, developmental stage, life cycle and health status. Although these aspects reside in the person, they are considered contextual because they are linked to sociocultural meanings. Environment refers to the physical aspects of space and place.

28 Impairment refers to the functional limitation within the individual caused by a physical, mental or sensory body structure or function problem (Yeo & Moore, 2003). This definition aligns with that proposed in the International Classification of Functioning (WHO, 2001a).

29 Body functions (for example seeing, hearing) and structures (for example eyes, ears) (WHO. 2001a)

30 Source: http://www.library/thinkquest.org/28028/lintloko.html. Accessed, 25 March, 2009.

meat wholesaler; running water to wash the heads and, cooked on an open fire, a sufficient supply of fuel (wood). Fetching the wood, a related occupation, is hard work because it usually has to be carried and transported by foot over considerable distances. Tools need to be sharpened; wood chopped and the fire stoked. Biopsychosocial[31] performance demands of this form of occupation on the developmental structure of the 'doer' include physical stamina, mobility, problem solving and endurance[32]. As discussed in the previous section, activity analysis enables occupational therapists to discern elements of form that may be adapted or modified so that the disabled individual can participate meaningfully in his/her life world. Very little has however been documented about occupational form in the context of a life world characterised by structural poverty[33].

2.2.4 Praxis: the dynamic process between the basics of occupation

The process of occupation is concerned with the dynamics of how occupation unfolds when actor and occupational form interact over time (Christiansen, 1999). People constantly move from one state of occupational engagement to another, occupying as if it were a state of liminality in which their attention, abilities and interests may be focussed on one or more human endeavours (forms of occupation) simultaneously. The process of occupation engages performance components such as thinking, feeling, moving as well as other biopsychosocial features such as a sense of self, cultural identity, and spirituality (Christiansen, 1999 , 2004). Other meta-determinants of human behaviour such as gender, race, ethnicity, history, ecology and politics indirectly influence the process of occupation at an individual level (Hocking, 2000b).

This means that particular indigenous ways of 'being' and 'knowing' are likely to influence the process of 'doing' and therefore 'becoming' (*inkambo*). For example, when the Nguni people of Southern Africa say about a person *uyaphila /o ea phela* (he or she has life), they are referring to more than biological life; the person has a relationship with his/her milieu (seen and unseen realm) that influences what is done and what happens in the doing space (Mkhize, 2004). The concept of 'person' in Xhosa culture is that of 'person-in-relation'

31 Biopsychosocial performance components refers to the biological (physical, physiological), psychological (cognitive, conative, affective) and social (intra and interpersonal) structures and functions of the individual (World Health Organization, 2001a)

32 An example would be working in the sun all day. This is contraindicated for certain psychotropic medication. The occupational performance demands of certain forms of occupation such as these require monitoring by health professionals working with psychiatric clients after discharge from hospital.

33 See footnote 28. It may be argued that little is known because the experience of living with the effects of structural poverty is unknowable by 'outsiders' or because this has, to date, been an unexplored domain of practice in occupational therapy.

(Mkhize, 2004, p 40). A sense of personhood is achieved through a process of being; it is an unfolding of *inkambo* and belonging through shared doing. A person finds meaning through participation in community. Ways of knowing are passed between the parts (individuals) and the whole (collective) through adherence to customs, symbols and rituals. The occupational form cannot be separated from the tacit processes underlying the performance of activities, tasks and social roles. In short, the occupational human is relationally defined because of the relationship between 'doing' and 'being'. In this instance, occupation transcends individual boundaries[34].

Picture 3: Occupation as process: cultural practices involved with slaughtering a goat

Picture 3[35] depicts the slaughtering of a goat for a cultural ritual. It shows aspects of occupational form (for example the tools and tasks involved with the actual slaughtering such as binding the animal, sharpening knives and preparing a fire), but guiding the occupational performance are tacit cultural practices and processes embedded in indigenous ways of knowing what to do, when, why, with whom and for what purposes. These processes are imbued with cultural motives and meanings for example, the markings on the slaughtered beast carry symbolic meaning and certain tasks such as slaughtering are gendered[36].

2.2.5 Purpose: the function and goal of occupation

The purpose of an occupation brings to the fore its goal directed application; it is a mechanism for achieving particular outcomes or objectives such as securing an income, a qualification, a created product or end result such as a work of art, a mowed lawn, a built wall, a fixed car or a baked cake. Occupation as mechanism involves focussed occupational performance in the

34 I am not suggesting here that there is an 'essence' of being part of a single, unchanging Xhoza culture that is easily distinguishable from and distinctive from all other cultures. This emphasis on connectedness and ritual is however a dominant feature of much writing on life in a Xhosa speaking community.

35 Source: http://www.library/thinkquest.org/28028/lintloko.html. Accessed, 25 March, 2009.

36 Fieldwork notes. Personal communication, S Gcaza, May 2006.

context of particular occupational forms.

Picture 4: Occupation as mechanism: selling intestines

Picture 4[37] is an example of occupation as mechanism. Here the purpose of selling *umbilini* (intestines) is to generate an income. The occupational form (for example the *umbilini,* the tools, working surfaces, transport to fetch supplies) and occupation as process (for example scraping and washing the *umbilini,* imbedded cultural values and knowledge about this food source, and the dynamics of making sales in a particular market place) and mechanism (means of income and potentially, building social capital) is implied.

2.2.6 Categories of occupation

There is general agreement across various taxonomies in occupational therapy that the main occupational performance areas are self care, productivity/work and leisure/play (Christiansen and Townsend, 2004a; Christiansen and Baum, 2005; Polatajko et al. 2004). Based on individualist perspectives[38] of time use, this categorisation sees humans as bounded, independent and autonomous systems that use time and fulfil social roles in time-structured ways (Farnworth, 2004). A clear distinction between these occupational performance areas is difficult because the priorities in what people do is constantly changing ie. how they choose to or are forced to spend their time, energy and resources depends on the dynamic interface between the personal, the social and the structural. Categories of occupation are not static. They blur as people respond to the emerging demands of life especially in cultures

37 Source: http://www.library/thinkquest.org/28028/lintloko.html. Accessed, 25 March, 2009.

38 Individualism is commonly presented as a Western way of viewing the world. This refers to mode of thought that has its origins in ancient Greek and European cultures (Cobern and Loving, 2001)

that adhere to collectivist[39] identities of self (Rudman and Dennhardt, 2008). Alternative categorisations of occupation exist for example social anthropologists categorise time use according to the utility of the activities that are performed. Aas (1980), in multi-cultural and multi-national time use studies, found that human lives across the world are remarkably regular, similar and systematic. He suggests that all human use of time, allocated according to utility and priority, falls into four broad areas or categories of endeavours: necessary (eg. sleep, eat), contracted (eg. remunerated productivity), committed (eg. childcare, meal preparation, shopping) and discretionary (ie. chosen during remaining time not spent on the other three categories). For the purposes of this study, these categories were interpreted as occupational performance areas and applied to a brief overview of occupations that were observed in Khayelitsha. Although it could be argued that Aas's (1980) categorisation schema is outdated, it was deemed suitable for the purposes of this study because it provides a more descriptive categorisation of the occupations that were observed in Khayelitsha than the extant taxonomies of self care, productivity and leisure in the occupational therapy literature.

2.2.6.1 Necessary occupations

Necessary occupations refer to those tasks and activities aimed at meeting basic physiological and self-maintenance needs that are required for health, hygiene, procreation and vitality (for example eating, sleeping, resting and personal care activities, such as bathing and grooming). Lack of infrastructure (for example decent housing, electricity and running water and low levels of income, literacy and employment) impedes the efficient performance of necessary occupations and suggests that unique combinations of occupations may be needed to achieve and maintain basic physiological well-being and self-care. For example, it takes much longer and more effort to get necessary things done when access to taken-for-granted amenities are under-resourced or absent (Moser, 1996). Taps and toilets have to be shared which means waiting for a turn; water has to be collected and transported by foot to a dwelling; substantial distances may have to be walked (or a wheelchair pushed) to access amenities; a fire has to be

39 Collectivist self is "a view of the self shared by many indigenous societies and non-Western cultures in which the self is fundamentally context-based, defined in terms of one's relationships with others, such as family, community, and status or position within the group. It is also understood as the interdependent notion of self" (Mkhize, 2004, p.27). Self care may, for example, be more than a series of individual activities and tasks that occur at the start or end of the day in a bedroom or bathroom; it may involve exchanging some form of capital while having your hair washed and braided by a neighbour in public at the nearest communal tap or while waiting for passing trade at a pavement stall.

lit to cook a meal and public transport is unreliable, costly or sporadic[40].

2.2.6.2 Contracted occupations

Contracted occupations typically involve some form of monetary or in kind gain. These occupations entail specific obligations for output by the doer matched to time spent on tasks set by the person themselves (if self employed) or by an external agency for example an employer or teacher (Aas, 1980). Productivity is central to human existence; not only may it yield material or non material gain of one kind or another (for example, an income; a qualification or bartered goods) but it also provides people with a social position, an identity and is, under optimal conditions, associated with good mental health (Rüesch, Graf, Meyer et al., 2004)[41]. Jobs in the formal economy tend to depend on some level of education for example being teachers, cashiers and bus drivers. These kinds of jobs may be beyond the reach of semi-literate and/or unskilled people who tend to find work in the informal economy[42]. Unemployed people in poor communities tend to gain their livelihood from a portfolio of casual jobs and income generating enterprises. The Jacaranda Report (2000) on small, medium and micro-enterprises in South Africa indicates that the informal economy consists of activities characterised as "domestic survivalist strategies" that contribute substantially to the economy. De Swardt, Puoane, Chopra and Du Toit (2005) argue that informal activities, while providing a marginal but essential lifeline for millions, often fall under the radar of income surveys, thereby distorting the data gathered about employment patterns in South Africa. People in Khayelitsha conduct contracted occupations from within their dwellings, from shopfronts attached to their homes, from pavement stalls or from commercial centres[43].

40 Structural poverty adds an additional layer of effort onto the challenges faced by disabled people who, in adjusting to the activity limitations that arise as a result of impairments, also have to find ways of overcoming the participation restrictions imposed by an underdeveloped context. Rehabilitation professionals, focussing on self care problems associated with impairments, must take this layer into consideration in their treatment and post discharge planning.

41 Workers, when comparing problems that arise from working (such as fatigue, unfavourable working conditions) as opposed to not working (such as financial hardship and boredom), reported that they much preferred to work than be unproductive (Rüesch et al, 2004; Harnois and Gabriel, 2000).

42 Some economists and social scientists contest the dualistic conceptualisation of the labour market arguing instead that formality and informality are opposite poles of a continuum; each extreme influencing the other (Devey, Skinner & Valodia, 2005; Lund, 2004).

43 Goods that are traded may include: sweets, biscuits, ice lollies, paraffin, cleaning agents, metal pot stands, timbers for informal houses, garden produce, mobile phones and accessories, ornaments, haberdashery items, spare parts for motor cars, beer (commercial and homebrewed), second-hand clothes, fish and meat (chicken pieces and feet, sheep's heads and feet, intestines, lungs), cooked meat and fresh produce, recycled rubble such as cardboard, glass and metal. Home industries may include running a shebeen (tavern), general dealer (for example selling small quantities of soap, milk powder, oil), dressmaking and tailoring, car and truck repairs, hairdressing, metal work, electrical installations and repairs, plumbing as well as constructing fencing and galvanised iron and timber dwellings and providing transport (passengers and goods).

The slide into poverty as a result of acquired disability (for example after an accident or a series of psychotic episodes) may be mirrored in the 'slide' of contracted occupations that the individual and/or household is forced to pursue (Bird & Shinyekwa, 2003). The slide may involve choosing occupations that are matched to the disabled person's residual abilities, usually from more to less demanding, from more to less resource dependent and sometimes from more to less economically viable. For example, a slide may entail downgrading from contracted occupations such as being a full time domestic worker to selling meat, then intestines, then chicken heads and feet, then sweets and eventually performing only committed occupations (defined in the next section) such as looking after children or running errands so that other members of the household are released to earn. Paradoxically, 'being disabled' and therefore bringing in a disability grant is in itself a committed occupation (this is discussed again later). Slides such as these also occur as part of the ongoing and dynamic ordering of a portfolio of household activities in poor, non-disabled households, often as result of some or other shock such as unemployment or a natural disaster such a fire (Moser,1996). Irrespective of the reason, the decisions people take about contracted occupations are complex and tempered by many extraneous events that are difficult to comprehend analytically[44].

2.2.6.3 Committed occupations

While committed occupations have a productive characteristic, they are not remunerated and are performed in unspecified, 'in-between' periods of time (Aas, 1980). These occupations support the efficient functioning of necessary and contracted occupations for example cleaning a house, sweeping a yard, collecting firewood, fetching buckets of water, chopping firewood, putting out refuse, shopping, using transport, walking between places, caring for elders and children and, in the case of children and youth, playing, doing homework or studying. Some people purchase the completion of their committed tasks by paying other people to provide these services for them, for example hiring a housekeeper, paying someone to do their laundry or to look after their children. Bray (2003) observes that while 'chores' are part of role development for children and involve a duty toward seniors and an opportunity to learn skills required in adulthood, the possibility exists that chores become work and children are thereby prevented from doing other things that are pivotal for their holistic development, such as play. Bray observes that this slippage is also gendered; boys may not be expected to do as much as girls in the home.

44 Vocational rehabilitation aimed at preparing disabled people to function in this context requires focussing intervention on a different set of skills than those needed for reintegration in the formal employment sector.

2.2.6.4 Discretionary occupations

Although discretionary or 'free time' occupations may include recreation, restorative or leisure pursuits, they are not necessarily linked to a sense of 'freedom from obligations'[45]. Free time can be increased (or reduced) by deferring or increasing responsibilities in the other three categories of occupation (Aas, 1980). Khayelitsha is a very busy place. Although there is a constant flow of people in the streets, their discretionary time use is analytically elusive and may, reportedly, include watching television (if electricity is available or affordable), visiting friends, congregating at music venues, eateries and shebeens or participating in sport (soccer is very popular) and religious activities. Discretionary activities also centre around cultural practices. When people move home or a family member is released from jail or dies, a household may call friends to a feast or ceremony, part of which involves the slaughter and cooking of the sacrificed animal to indicate to ancestors where the individuals concerned can be found in temporal space and place (Guma, 2004).

2.2.7 Occupational injustice: deprivation, alienation and imbalance

Poverty (amongst other adverse social conditions) deprives people of the resources needed to engage in a range of occupations commensurate with their needs, aspirations and potential. It may prevent essential and meaningful activity related processes from occurring that add value to their life and is likely to decrease the opportunities through which occupation can be used as a mechanism for the attainment of personal ambitions. Occupational scientists argue that people under these circumstances are subject to occupational injustice which may be identified in three forms: occupational deprivation, alienation and imbalance[46] (Whiteford, 2000, 2004; Wilcock and Townsend,2000; Wilcock, 1998a;). The concepts of occupational deprivation, alienation and imbalance, in particular combinations and forms in the context of poverty, imply a scarcity in range, scope and variety of "doing" that in turn may create a barrenness of "being" and diminish the hope of "becoming"[47]. Poverty, by restricting peoples'

45 Leisure enhancement is extensively addressed in the occupational therapy literature. The profession has been associated with counteracting boredom and institutionalisation, especially in psychiatric hospitals, through providing enriching occupational engagement opportunities (Long, 2004). If occupational therapists are to provide contextually relevant services in collaboration with psychiatrically disabled people they need to know more about the impact of structural poverty on boredom and on the choices available for discretionary occupations in marginalised communities.

46 Occupational deprivation is defined as "a state of prolonged preclusion from engagement in occupations of necessity and/or meaning due to factors which stand outside the control of the individual" (Whiteford, 2004, p. 222). Occupational alienation as "a sense of isolation, powerlessness, frustration, loss of control, and estrangement from society or self as a result of engagement in occupation that does not satisfy inner needs" (Wilcock, 2006, p. 343). Occupational imbalance refers to disruption of balance or equilibrium within and between intrinsic and extrinsic physical, mental and social capacities (adapted from Wilcock, 1998a).

47 Many poor people do however rise above these forms of adversity. Aspiration, resilience and agency is addressed later.

choices and opportunities to develop their potential, creates a specific type of developmental impoverishment, which has a profound impact on the health, function and wellbeing of individuals and communities. The reverse also applies. Disability compounds the effects of poverty. Both disability and poverty have intergenerational repercussions (Hobcroft, 2007; Hulme, 2003).

Wilcock (1998a, p.163) suggests that lack of becoming, as a factor in illness, arises from insufficient attention to "the relationship between what people do, how they feel about what they do, and whether or not they can realise their goals and actualise their potentialities". Whether or not people can realise their goals and actualise their potentialities is closely associated with the way society is structured including their access to social justice. Occupational therapy, in seeking to be more contextually relevant and socially responsive has been theorising its emerging role in promoting social justice (Townsend, 1993). Townsend and Wilcock (2004a,b) propose an exploratory theory of occupational justice that consists of three interconnected pillars: occupational determinants (for example type of economy, policies, values operating in particular contexts), occupational forms (for example opportunities and restrictions imposed by structural developments) and the outcomes of occupational injustices (for example the health and social consequences of deprivation, alienation and imbalance). They argue for a practice focus by occupational therapists on the "rights, responsibilities and liberties of enablement related to individual, diverse occupational needs, strengths and potential" (ibid, 2004b, p.244). Just how this might be achieved in the context of chronic poverty presents a horizon of development for the profession. Given the paucity of occupational therapy and occupational science literature on poverty the next section of this chapter briefly reviews various theories about and approaches to poverty.

2.3 POVERTY

Implemented in a peri-urban informal settlement on the outskirts of a major South African city, this study foregrounds individual experiences of and responses to poverty through the everyday things that psychiatrically disabled people and their households do for self-provisioning. While their survival stories are uniquely theirs, they are not alone. More than a billion people, one in five, in the global south live on less than US$1 a day; their poverty precipitated and perpetuated by complex socio-political and economic systems that control the distribution of the world's resources. According to Bush (2007, p. xiii) "people in the Global South are poor because of the ways in which the economies in which they live have been incorporated into the world economy". It is beyond the scope of this report to review the

seminal social, political and economic theories that explain wealth and poverty creation[48]. A review of the poverty literature, pertinent to the qualitative description of the occupations of poor and disabled individuals, must however start with an acknowledgement that poverty is a complex, multi dimensional social phenomenon that is associated with discursive systemic forces which shape the unequal and unjust distribution of power, privilege and resources.

The causes and consequences of poverty are complex and have been extensively documented. From an occupational therapy point of view poverty cannot be understood apart from the personal histories of individuals and the ways in which they are incorporated into particular local socio-economic and political systems that are, in turn, shaped by national and global systems that control and curtail their access to the resources and opportunities they need to thrive. Viewed against this backdrop, poverty deprives people of the choices and opportunities they need for optimal participation in life by limiting what they are able to do, to be and to become. It is ultimately about the value that is placed on human life and the "deprivation of human capability of essential opportunities and choices needed for the well being of an individual, household or community" (United Nations Development Programme, 2002; p.94). This perspective is one of many possible ways of conceptualising poverty. In the 1960s poverty was defined as a low income problem and in the 1970s it was associated with relative deprivations of basic needs[49]. In the 1980s non-monetary concepts such as

48 Bond (2007) maps five international political currents that influence how social justice is understood and the distribution of wealth and poverty may be conceptualised. These currents range from socialism and anarchism on the left through capitalism, social democracy and neoliberalism in the centre to neo conservativism on the right. Global justice movements, supporting socialism in the fight against poverty, argue for deglobalisation of capital (not people), anti-racism, women's liberation, decommodified state services and radical participatory democracy. Third World nationalism, supporting national capitalism, argue for fairer global integration, expanded market access, reformed global governance, Third World unity and anti-imperialism. The Post Washington consensus movement, supporting social democracy, opposes the United States unilateralism and militarism and advocates for sustainable development via United Nations and similar global state-building frameworks. The Washington Consensus lobby, supporting neoliberalism, argue for the inclusion of emerging markets under the umbrella of a US-led Empire. The main agenda of neoconservatists is the defence of particular rightwing ideologies including religious extremism, patriarchy, unilateral petro-military imperialism and globalisation of people via racism and xenophobia. It is beyond the scope of this study to review these ideological currents, the philosophical tenets on which they are based and their role in creating, perpetuating or alleviating poverty. Suffice to acknowledge that the conceptual and theoretical terrain of poverty is complex and highly contested amongst the proponents of different philosophical schools. Poverty in South Africa must be seen against the backdrop of the country's colonial and apartheid history; its position as a fledgling constitutional democracy and its economic contribution to development in Southern Africa.

49 Basic needs refers to the means required for individuals to achieve some functionings ie. the minimum that an individual requires to fulfil his/her humanness (De Haan, 1998).

vulnerability[50], livelihoods[51] and capabilities[52] were included in definitions and measures of poverty. Notions of 'voice', 'well-being' and participation were introduced during the 1990s. A human rights-based, developmental approach has dominated poverty debates in recent years[53]. Underpinning the various definitions and approaches are socio-political issues of inequity, exclusion and underdevelopment (Scott, 2002). Explanations for poverty include overcrowding, lack of skills and low productivity and international dynamics such as market economies and globalisation (Banerjee, Bénabou & Mookherjee, 2006; Chronic Poverty Research Centre, 2004b). Social causes include discrimination on the basis of ethnicity, gender, ability and age and high fertility rates leading to a range of problems such as poor health, class inequality and a culture of poverty (Alcock, 1997; Narayan et.al., 2000a,b). Political causes and consequences point to incompetent governance, corruption, civil war and violence (Bush, 2007), while environmental factors include depletion of limited natural resources, ecological degradation and living in remote regions or being forced to live in areas where natural disasters frequently occur (Alcock, 1997; Banerjee, Bénabou & Mookherjee, 2006). Two approaches to poverty are briefly reviewed with due consideration of disability and occupation where indicated.

2.3.1 Poverty as material deprivation and asset depletion

The basic needs concept of poverty is based on the premise that material and physiological deprivations such as lack of income, food, clothing and shelter compromise the survival capacity and health status of people. A core set of minimum requirements for living such as housing, water, healthcare and transport is adopted as the measure of development. Du Toit (2005a) argues that definitions of poverty cannot be collapsed into indicators that are ostensibly 'scientific' and based on 'objective reality', such as the cost of a minimum food

50 Vulnerability refers to the susceptibility of individuals, households and communities to sudden shocks or longer term stresses imposed by changing economic, environmental, social or political circumstances (Meikle, 2002).

51 Livelihood refers to the way in which a household meets its present and future needs and pursues its aspirations (Hulme, Moore and Shepherd, 2001, p. 25). Livelihood comprises assets (natural, physical, human, financial and social) and the capabilities that people have to access to these assets (mediated by institutions and social relations). Assets and capabilities combine to determine the living gained by the individual or household (Ellis, 2000a, p.10).

52 Chambers & Conway (1992, p.7), writing within the Sustainable Livelihood Framework, define capabilities is a "set of alternative 'beings' and 'doings' that a person can achieve with his or her economic, social and personal characteristics". Capabilities comprise the assets (stores, resources, claims and access) and activities required for a means of living. Sen (1999, p. 40), writing within the development framework, sees capability as "a set of vectors of functionings, reflecting the person's freedom to lead one type of life or another". Both these definitions, arising from different perspectives on poverty, recognise that people are capable of acting on and in their world when they have access to both internal (subjective, personal) and external (objective, structural) resources.

53 Rights based approach is an approach to human development based on understanding the links between development and civil, political, economic, social and cultural rights (DFID, 2001).

basket, nutritional status, weight-height rations, dietary needs and calcium intake and then aggregated into a measure of a social condition. He points out that these so-called 'socially accepted necessities' are themselves value-laden and tend to deflect attention away from the causal dynamics in poverty. Material deprivations are ultimately linked to social experiences of voicelessness, powerlessness and alienation. People who are hungry by virtue of their position in society are also people without a voice in society, the materiality of their everyday life reflecting their marginalisation and oppression. The additional burden of disability (and for example gender in the case of some women or ethnicity in the case of refugees) compounds the degree of deprivation and voicelessness that may be experienced by poor people.

The Sustainable Livelihoods Framework is an analytical tool for assessing the availability or depletion of assets on which people draw to meet their various needs and aspirations (Kaag, 2004; Rakodi, 2002) [54]. A livelihoods analysis of poverty uses objective and subjective assessments of the choices people make and are able to make by virtue of their available assets and resources, the risks they face, the insecurity and vulnerability of their circumstances and the strategies they use to cope with life changes (Chambers & Conway, 1992). Objective livelihood assessments are based on the premise that individuals are rational and the best judges of the sort of life they want and the kinds of activities that maximise their utility and happiness. Subjective assessments of livelihoods are people centred and attach value to what poor people themselves prefer and what they say about their poverty (Kaag, 2004). A household's level of livelihood security[55], quality of life, and its coping strategies[56] can be assessed in terms of assets or various forms of capital (see footnote 54) that may be accumulated, exchanged, expended, depleted and lost (Frankenberger et al., 2002). A

54 Livelihood comprises assets and resources (natural, physical, human, financial and social) and the capabilities and the access to these (mediated by institutions and social relations) that together determine the living gained by the individual or household (Ellis, 2000a, p.10). Resources are categorised as forms of capital. Capital refers to the tangible or intangible assets that are held by a person or household for use or investment. It is any source of benefit, assistance or wealth, in whatever form, that can be used to produce more wealth. It may be physical (for example house, livestock), financial (for example wages, rents, savings); human (for example education and health), natural (for example land, water, trees), social (for example kinships and social networks) and political (for example franchise) (Ellis, 2000 a,b).Various forms of capital can be accumulated, exchanged, expended and lost, thereby affecting a household's level of livelihood security, quality of life, and its strategies for coping (Frankenberger et al, 2002).

55 Livelihood security refers to the adequate and sustainable access to income and other resources to enable households to meet basic needs, such as water, food, educational faculties, housing, time for community participation and social integration (Ellis, 2000a, p15). Security refers to stability and continuity of livelihood, predictability of relationships, feeling safe and belonging to a social group (Narayan, Chambers et al, 2000).

56 Coping strategies, in terms of livelihoods, refer to a set of actions that aim to manage the costs of an event or process that threatens the welfare of some or all of the household members. Coping strategies seek to sustain the economic viability and sustainability of the household (Sauerborn, Adams & Hein, 1996). Humans as occupational beings however also make use of other types of coping strategies for example using psychological defence mechanisms and behavioural adaptations to deal with life stressors or making physical modifications to occupational forms to enable or support performance and participation. Chapters 4 & 5 illustrate this point.

livelihood is considered sustainable when it can cope with and recover from stresses and shocks as well as maintain or enhance its capabilities and assets, while not undermining the natural resources base (Ellis, 2000a,b; Chambers & Conway, 1992).

A distinction between the concepts of 'livelihood' and 'occupation' is warranted because both are concerned with what people do every day to meet their needs. Table 1 compares dimensions of 'livelihood' and 'occupation' as described in the literature.

Table 1: Dimensions of livelihood and occupation

DIMENSION	**LIVELIHOOD** (Ellis, 2000a,b; Kaag, 2004)	**OCCUPATION** (Kramer *et al*., 2003; Wilcock 2006)
Epistemology	Social, economic and development science; Multidisciplinary focus on people's day to day actions aimed at making or earning a living; Theories explaining how people acquire the means of human welfare, productivity, investments and returns; Homo economicus.	Humanities and health sciences Multidisciplinary focus on humans as actors in their lived environments Open/dynamic systems theory that explains how and why human action occurs through the structure and function of the body in dynamic exchange with the environment; Holism (humans as total beings acting in and on their environment) Homo habilus.
Definition	The actions and strategies people use when trying to make a living; Comprises activities, capabilities and assets (stores, resources, claims, access) required for making a living.	The ordinary and familiar things people do everyday; Comprises purposeful and meaningful activities, tasks and roles that engage the biopsychosocial functions, structures and skills of the doer.
Core constructs	*Capitals:* tangible or intangible assets that are held by a person or household for use or investment. It is any source of benefit, assistance or wealth, in whatever form, that can be used to produce more wealth. *Assets:* natural, physical, human, financial, social and political capitals *Strategies:* activities that generate the means of household survival by mobilising available resources and opportunities *Access:* rules, social norms and values (e.g. gender, class) that determine whether and how people can own, control, claim and make use of resources; *Income:* cash or in-kind contributions to material welfare deriving from a set of livelihood activities.	*Being:* essential nature, core, essence, substance of the human, his/her inner person, existential *Doing:* action; acting with intent; creativity; active performance *Becoming:* process of change; to unfold or come into being; *Function:* the way occupation is undertaken, why it is undertaken and whether adaptation occurs or not *Form:* directly observable actions & objects/ materials etc. that make it recognisable to outsiders in terms of socio-cultural conventions and values; *Meaning*: what the occupation symbolises to doer; the perceptual, cognitive and affective experiences elicited by the doing; *Purpose:* goal orientation of human actions.
Purpose	Generate the level of income & resources needed for survival. Risk management	To exercise biological drive to act on and in the world.
Focus	Social foundations of economic behaviour;	*Means* through which humans act in and on the their environment The *end* towards which human 'being', 'doing' and 'becoming' strives, ie. 'occupacio' (occupied and engaged)
Process & outcomes	Livelihood is not just net results of income received or consumption attained, it also refers to ways in which a living is secured/ obtained over time	Realising human potential Participation in life

The main points of departure in Table 1 is that occupation, as a construct, focuses on the essential features of what occupies people's time including the use of their developmental structure (see footnote 7) to perform the activities and tasks associated with particular social roles. It is the form and process (ie. building block) through which humans act in and on their world and is, as such, a mechanism through which livelihood may be secured. The main resource poor people have available for securing livelihood is themselves ie. their labour, time and skills. This implies particular configurations of occupation are needed in the context of poverty to make a living and to ensure survival, a point that occupational therapists concerned with work rehabilitation of poor and disabled people need to consider[57].

Livelihoods analysis however involves more than a cumulative enumeration of intra- and inter-household coping strategies and assets. It also recognises that the value of asset capitals resides in the broader relationships, practices, institutional and discursive formations within which these capitals operate. The inequalities of power between communities or between the poor and local elites and government agencies influence the robustness of people's livelihoods. Du Toit (2005a) points out that a household's access to resources is mediated by social networks and connections that extend beyond household members and non-members and is highly fluid and tenuous. Any attempt at capturing livelihood information quantifiably is likely to yield incomplete data about the structural systems that underpin and influence people's livelihoods, especially the risks and vulnerabilities associated with marginalisation and social exclusion. An occupational lens suggests that these risks and vulnerabilities affect the developmental structure of individuals in particular ways.

2.3.2 Poverty as ontological deprivation and lack of freedom

The human needs[58] approach sees poverty as something that happens inside people as a consequence of what happens between people in society. Their environments and support systems become eroded as a result of complex social processes leading to human poverties

57 The point here is that particular configurations of occupation may impact adversely on health, personal development and well-being. The notion of "occupational security" has not been mentioned in the occupational therapy/science literature but, in view of the discussion here about livelihood security, it may be argued that the stability and continuity of the ordinary, everyday things that people have to do in order to meet their basic needs in the context of poverty ie. their occupations, depends on access to adequate and sustainable personal (internal, subjective) and structural (external, objective) resources. In the absence of this security, people may experience occupational poverty, a concept described by Duncan and Watson (2009) as a state of existence characterized by stagnated potential, stunted agency and restricted learning. It is precipitated and perpetuated by structural inequity and injustice and occurs when people are deprived, over long periods of time, of opportunity, choice and variety in daily activities, tasks and roles. Occupational poverty may occur as a result of the simultaneous and prolonged experience of occupational deprivation, alienation and imbalance (see footnote 46 for definitions).

58 Writing from an occupational science perspective Wilcock (2006, p 28) describes human need as "a central motivating variable" that acts as an innate force or drive for human action" (Wilcock, 2006, p. 28).

evident at a material and social level. Max-Neef (1991, p. 24) posits an ontological perspective by defining poverty as "any fundamental human need that is not adequately satisfied". The realities of poverty, illness and despair can, according to Max-Neef, be traced back to the dynamic between nine fundamental human needs (subsistence, protection, affection, understanding, participation, idleness, creation, identity, freedom) and four human values of 'doing', 'being', 'having' and 'interacting'. He argues that economists classify basic needs in terms of goods and services in the market, such as housing, electricity and water and then worry about the money to pay for them. Max-Neef (1991, p. 25) explains that while material goods are legitimate concerns, they are "not the only domain where human need is satisfied". He believes that most human needs can be satisfied without spending large amounts of money and are often satisfied in situations where people are not choked by excesses of wealth and materialism, which Max-Neef calls the 'poverty of plenty' scenario. The ontological approach to poverty is aligned with the humanistic and holistic philosophy of occupational therapy and occupational science because it views humans as complex, integrated whole beings with physical, social, cognitive, psychological and spiritual dimensions[59].

Also concerned with the nature and essence of things that affect human freedom, Sen (1999, p.39) sees living as a set of interrelated 'functionings' that consist of 'beings' (for example being happy, not being ashamed, having self respect, being literate, healthy, well fed and clothed) and 'doings' (for example taking an active part in the community, travelling, voting). A person's achievements in 'doings' and 'beings' can be seen as the vector of his or her functionings, which, according to Duclos (2002), are the constitutive elements of well-being. Sen argues that it is not possible to achieve well being or to live a full and free human life without access to 'doing' and 'being' capabilities[60]. He states that "the capability to function represents the various combinations of functionings (beings and doings) that the person can achieve" (ibid, p 40). Poverty, under these circumstances, is "the lack of freedom to do certain valuable things" (Sen,1999, p. 5). It exists when people lack capabilities, both intrinsic (for example personal, individual attributes) and instrumental (for example health, income, education and political rights). The lack of capabilities prevents or constrains people from attaining certain functionings (things they want to do) and beings (states of existence they

59 Kramer, Hinojosa & Royeen (2003, p. 40), in discussing holism and the philosophical roots of occupational therapy, suggest that the profession considers human needs to be ontological, that is, "they originate from the existential essence of the whole person in context".

60 Capability is "a set of vectors of functionings, reflecting the person's freedom to lead one type of life or another" (Sen, 1999, p. 40).

want to experience) [61]. The capability approach to poverty focuses on what poor people have as opposed to what they do not have. It explores the extent to which a person has the right and the freedom to choose what s/he desires in all matters concerning their own lives. In so doing, it emphasises empowerment, expanding opportunities and eliminating social constraints and places the onus on society to create enabling, inclusive physical environments and social conditions for its citizens, irrespective of their class, gender, ethnicity, ability and other features of human diversity. By balancing the integrated development of human capacity on the one hand with service delivery on the other, the capabilities approach to poverty eradication focuses on creating optimal social systems for example public works programmes, grants and adult literacy programmes. As such it provides a useful framework for the disability agenda in development work (Mitra 2005, p 8) and supports occupational therapy commitment to collaborate with disabled people for the creation of equal opportunities and inclusive participation in society (Kronenberg et al, 2005). The capabilities approach is also aligned with the vision of occupational justice proposed by Townsend and Wilcock (2004a,b) and the political agenda of occupational therapy (Pollard, Sakellarious & Kronenberg, 2009).

2.3.3 Configurations and forms of poverty

In an attempt to differentiate temporal configurations of poverty, Hulme and Shepherd (2003b) developed a typology that distinguishes between the always poor, usually poor, churning poor, occasionally poor and the never poor. The distinctions between degrees of poverty have been critiqued because they are based on an arbitrary understanding of the social dynamics that trap people in powerless positions and the time (sometimes decades) that it takes them to climb out of poverty (Bevan, 2004; Du Toit, 2005b). Stevens (2003) used the Hulme and Shepherd typology in a four year, mixed methodology study of 200 households in urban areas of Gauteng, South Africa and found that it was possible to distinguish between these degrees of poverty using the Household Subsistence Level (HSL) [62] as a poverty line. Stevens (2003, p. 5) points out that the difference between transient and chronic poverty is not necessarily its depth, but its duration.

The chronically poor are those people who experience poverty for extended periods of time or throughout their entire lives, whose children are also likely to remain poor, and who have benefited least or are likely to benefit least from economic growth and national and

61 Capability deprivation is a form of poverty defined by a failure to achieve basic capabilities such as being adequately nourished, leading a healthy life or partaking in the life of the community (Sen, 1997).

62 The HSL (household subsistence level) estimates the income needed by an individual household if it is to maintain a minimum level of health and decency in the short term.

international development initiatives (Chronic Poverty Research Centre, 2004b). Hulme, Moore and Shepherd (2001) suggest a period of five years and more as their criterion for chronic poverty during which time the household may experience fluctuations in average income well below the adopted poverty line for more than 50% of the time. Chronic poverty may also be intergenerationally[63] transmitted (CastaEeda and Aldaz-Carroll, 1999). The chronically poor are most likely to be found in remote rural areas, urban ghettos and regions of prolonged violence and are usually individuals and groups who are socioculturally susceptible to discrimination and exclusion. Factors such as gender, ethnicity, spatial location, stage of lifecycle and intra household status, cultural roles and identity all play a part in perpetuating disadvantage for certain groups of people.

Structural poverty refers to the complex social dynamics and power relations that limit the (re)distribution of resources in society and adversely influence the restructuring required for social development (Bhorat & Kanbur, 2006). Structural poverty is shaped and maintained by interactions between asset poverty, cash hunger, job insecurity, unemployment, the thinness and ambiguity of social capital and subjection of marginalised people to exploitation (Adato, Carter and May, 2004). Deeply systemic ideologies, the legacy of apartheid and colonialism, continue to influence the ways in which individuals and groups are able to access resources, thereby making escape from poverty for a large segment of the South African population very unlikely (Stevens, 2003). Although the South African labour market no longer discriminates on the basis of race, the poor (who as a result of apartheid predominantly constitute unskilled and undereducated Black people) continue to be excluded from development opportunities. They have little besides their physical labour to contribute to development because they do not have the requisite training or skills for a market driven economy. Deprivations that derive from social exclusion (for example spatial segregation of vulnerable groups living in informal settlements and structural issues such as racism and sexism in the employment sector) impede people from participating fully in society and therefore its development.

Poverty (and disability as will be discussed later) itself may also be seen as a socially excluding phenomenon. Even if financial and other resources flow into various sectors of society, poor (and disabled) people do not access them due to structural barriers such as geographical isolation, lack of health, poor education and limited political power. Du Toit (2005b) points out that the poor do participate in the economy but that the prevailing structure of the South African labour market can worsen their poverty and vulnerability because it does not provide

63 A generation is set at 15 years.

the conditions within which their agency and potential productivity can be optimised[64]. Structural poverty introduces particular forms of vulnerability and risk into occupational form and therefore warrants attention by occupational therapists working with poor and disabled people in marginalised sections of society (Kronenberg Lorenzo, 2006).

2.3.4 Poverty, vulnerability & risk

Poverty and vulnerability are two different yet dynamic, intertwined processes that are constantly being altered or reinforced by each other. Vulnerability, according to Moser (1996), has two dimensions: an external dimension of risks, shocks and stresses to which the individual or household is subject; and an internal dimension in which people are unable to cope with, or respond to external pressures without suffering damaging loss. Shocks such as illness, natural disasters, prolonged unemployment, death of the breadwinner that can catapult vulnerable individuals and households into declines that may result in catastrophe (hunger, starvation, family breakdown, destitution and even death) (Moser,1996). Shocks may also precipitate a 'downscaling', adjustment or diversification of livelihood activities in response to the risks faced by the household. In short, vulnerability is the underlying propensity to risk[65] and the ease with which a system, household or person can recover from adversity.

Vulnerability and robustness/resilience are two different properties of systems[66]. A robust system recovers quickly, a vulnerable system less quickly. Vulnerability may be increased by a lack of assets or by the inability of people to use the assets at their disposal when faced with the negative consequences of unexpected or unavoidable change, for example, the onset of psychosis or a fire that burns down a dwelling (a frequent occurrence in overcrowded informal settlements). Some people are at risk of becoming poor because of vulnerabilities beyond their control, such as disability, gender or living in rural areas. Migration between rural and urban locations may compound vulnerability and risk. Kothari (2002) suggests that

64 This raises questions about the role of social grants in offsetting the effects of structural poverty on skilled disabled people, who despite the political and policy agenda for full inclusion and equal participation of disabled people in society, may never be able to get a job in the formal labour market because jobs are scarce for everyone (Ngwena, 2006). The impact of poverty on the development trajectory of unemployed people therefore warrants attention by occupational therapists concerned with the reintegration of disabled people into the workforce. Alternative models of work rehabilitation, focussing on the informal or the public works sector, may have to be considered.

65 Risks refer to uncertain events that can lead to welfare loss (Prowse, 2003).

66 Vulnerability refers to the "insecurity of well-being of individuals, households or communities in the face of a changing environment" Moser (1996, p. 2). Resilience has three defining characteristics: the amount of change a system (in this instance the household) can undergo and still retain the same controls on function and structure; the degree to which the system is capable of self organization and the ability to build and increase the capacity for learning and adaptation (Berkes, Colding and Folke, 2003, p. 13).

poor people cannot dictate their location, thereby exposing them to greater risk. According to her, "many people cannot move because of systemic, structural and individual reasons that reflect their experiences of exclusion or adverse incorporation. These include domestic and familial obligations and responsibilities, disability and illness, age, lack of education and skills, and an absence or lack of access to networks and relationships. The movers and stayers alike are deeply embedded in specific economic and social-relational contexts" (Kothari, 2002, p. 14-15). Disability in particular renders poor people vulnerable because they have to contend with stigma, prejudice and social exclusion. Thus, not only is their social capital reduced but their access to financial capital is also limited (Mitra, 2005). Nussbaum (2000), writing from a capabilities approach to poverty and development, argues that marginalised groups, especially women, internalise low possibilities for themselves because of their life experiences. Internalised feelings of powerlessness compound the impact of disability and poverty because both these human conditions reinforce the stigmatisation of difference and powerlessness.

Social exclusion, a feature of vulnerability amongst the poor and a common experience of disabled people, does not mean that excluded people are outside the functioning of the included segments of society (Emmett, 2006). What it may mean is that they are adversely included (Kothari, 2002). According to Du Toit (2005b, p. 13) "the problem is not that poor people have simply been excluded from particular institutions, resources or larger processes, but that they have been included on inequitable or invidious terms". For example, the vulnerable poor at the margins of the formal economy are those whose labour is expendable in the commodity chain, whose jobs may be seasonal and subject to the whims of the economic market, and whose labour is unregulated by the State. Adverse inclusion also applies to disabled people (see footnote 64). Seirlis and Swartz (2006, p. 364), in writing about the pitfalls of employment equity and reasonable accommodation in the workplace for disabled people, state that "persons with disabilities (along with many black people and women) have had far too many experiences of being tolerated as a 'requirement' or of being cynically used as 'window dressing' for us to underestimate the importance of attitudes".

2.3.5 Poverty and well-being

Well-being is a subjective state of wholeness that is evidenced objectively in the way a

person functions[67]. As has been discussed previously, poor people do not have access to the fundamental pre-conditions for human well-being. To be poor means to go short materially, socially and emotionally (Shore, 1997). It means not having "the tools to build the blocks for the future – your 'life chances'. It steals away the opportunity to have a life unmarked by sickness, a decent education, a secure home and a long retirement" (Oppenheim & Harker, 1996, cited in Alcock, 1997, p. 3). In short, to be poor is to live in a constant state of ill-being. Narayan, Patel et al., (2000b, p. 2) in a study of the experiences of poor people in 58 countries in the developing and transitional world, identified the following ten interlocking dimensions of powerlessness and ill-being associated with poverty:

- livelihoods and assets are precarious, seasonal and inadequate;
- places of the poor are isolated, risky, un-serviced and stigmatised;
- the body is hungry, exhausted, sick and poor in appearance;
- gender relations are troubled and unequal;
- social relations are discriminating and isolating;
- security is lacking in the sense of both protection and peace of mind;
- behaviours of those more powerful are marked by disregard and abuse;
- institutions are disempowering and excluding;
- organisations of the poor are weak and disconnected;
- capabilities are weak because of the lack of information, education, skills and confidence.

The South African Participatory Poverty Assessment (SA-PPA, 1998) reports that the poor in South Africa characterised poverty as having the following dimensions:

- isolation from family and community institutions;
- inability to provide food in sufficient quantity and quality;
- living in overcrowded and poorly maintained homes;
- lack of access to safe and efficient sources of energy;
- lack of adequately paid or secure jobs;
- fragmentation of the family;
- vulnerability to shocks such as the death of the main earner or environmental hazards such as flooding.

67 Well-being has been defined as "a general term encompassing the total universe of human life domains including physical, mental and social aspects (Education, Employment, Environment., Etc) that make up what can be called a 'good life'. Health domains are a subset of domains (Seeing, Speaking, Remembering, Etc.) that make up the total universe of human life" (World Health Organisation, 2002, cited in Wilcock, 2006, p. 310).

Clearly, the powerlessness, marginalisation and deprivation that poor people experience and the descriptions they give of the poor life are similar irrespective of where they live. Disability and other forms of social oppression (for example those pertaining to gender, race and sexual orientation) are likely to aggravate the depth of these experiences.

Graham and Pettinato (2006) point out that research shows little correlation between aggregate economic growth, happiness and a sense of well-being. There is no evidence that happiness increases as societies grow wealthier or that happiness differs between wealthier and poorer societies. People's sense of well-being depends as much on income as it does on factors such as having a job, being healthy and having supportive social relationships. Objective macro economic and political variables such as unemployment, inflation and civil volatility also negatively affect people's subjective perceptions of well-being, thus making good governance, democracy and social stability important factors in enhancing well-being (Graham & Pettinato, 2006). According to Du Toit (2005a, p. 20), the scope for transformation out of poverty requires an engagement "with ways in which structure provides the conditions of possibility for agency … with ways in which people are enabled to make sense of their situations – as individuals, as groups, as office bearers and officials – in order to act upon them". While the conditions for promoting the agency of marginalised people may be made available as part of an enabling society, people's ability to act on such opportunities is significantly influenced by their perceived sense of agency and well-being, which paradoxically, is eroded by the conditions of marginalisation within which they find themselves. Given what poor people have to say about their lives and experiences it is clear that social, physical, spiritual and mental well-being only work in unison to create 'the good life'[68] or at least a 'better life' when people have access to the opportunity structures within which to apply their agency (Nayaran, 2005). The political agenda of occupational justice paves the way for occupational therapists to appreciate their potential contribution to the creation of a better life for people marginalised by structural poverty and disability (Pollard et al. 2009).

68 Ecological models of adaptation, well-being and wellness suggest that "people thrive when their personalities and needs are matched with environments or situations that enable them to remain engaged, interested and challenged" (Christiansen & Townsend, 2004b, p. 23). Hasselkus (2002) links 'the good life' to positive health, active living and a sense of coherence synthesised through occupation. People enduring material hardship and structural poverty are engaged, interested and challenged; they do live actively and develop a sense of coherence synthesized through occupation; they may even have good health but life for them cannot be described as good because they can seldom thrive under or escape the ceiling placed on their aspirations and potential by factors beyond their control.

2.3.6 Poverty and households

Households[69], are the most common units of analysis in poverty research. The concept of a 'household' is difficult to define because it represents a diversity of residential forms, groupings of people and functions. To circumscribe the conceptual entity as a 'nuclear' or 'extended' family negates the developmental cycle of the unit itself because households, particularly in peri-urban informal settlements and rural areas, change shape and size constantly in response to social pressures and financial imperatives. According to Bolt and Bird (2003), writing on interhousehold differences and inequalities in the context of chronic poverty, there are many competing voices in every household, each with his/her own interests and perspectives and each ready to bargain, negotiate and struggle for access to resources. Householders do not necessarily live together nor do they always get on with each other; their behaviour within the household unit being linked to cultural norms, unconscious social processes and discursive influences. Whatever inter-household relationships are, the social identities that people inhabit by virtue of how they are situated in the household influences what they are able or expected to do every day (Beall & Kanji, 1999).

The fluid size, composition and location of a households is linked to a range of pursuits by different members, moving within and between residential places and spaces and contributing in different ways to the economic viability of the unit[70]. A household may seek to gain members in the hope of increasing its array of income sources, human and social capital (Russell, 2004). For example, rural household members may support their urban counterparts with subsistence products or by caring for children for a season so that the 'middle generation' (working age adults) can earn an income to be sent back to rural units by way of remittances. Bidirectional flow occurs not only between rural and urban linkages, but also between household units within urban and rural geographical spaces. This arrangement applied to all the households involved in this study. The fluidity of household membership as well as the complex psychosocial dynamics that operate between members and between various households within a clan social system affect children, disabled and elderly people who have access to social security. They may be moved between dwellings and extended units so that different parts of the household can access a social grant income (Lund, 2006; Stevens, 2003). This may place disabled people in a paradoxical position: they are dependent on the physical care and support of other householders who are, in turn, dependent on the

69 See Chapter 1 page 2, footnote 6 for definition and description of household.

70 Discussed further in Chapter 4.

disabled person for financial support[71].

2.3.7. Poverty and disability

Disability, according to Mitra (2005, p.1), occurs when "an individual with an impairment is deprived of practical opportunities and results from the interaction between resources available to the person, personal characteristics (type of impairment, age, gender etc) and the environment (physical, social, cultural, political, economic etc.)". According to the World Bank (2000) disabled people account for one in five of the world's poorest. Elwan (1999) in an extensive survey of the poverty and disability literature found the following: 1) information about disability is scarce in developing countries; 2) disability is a relative term and its measurement is beset with lack of valid and reliable instruments making comparisons of prevalence and incidence within and between countries difficult; 3) disability rates appear higher in rural than urban areas; 4) female rates of disability are higher possibly due to poor health care, nutrition and multiple pregnancies or females may die earlier in childbearing age groups; 5) disabled people tend to have lower education and income levels below the poverty line; 6) accidents and conflict are important causes of disability; 7) correlations exit between disability and age, education, income, ethnicity, living arrangements and gender and 8) disabled people make up between 15-20 percent of the poor in developing countries.

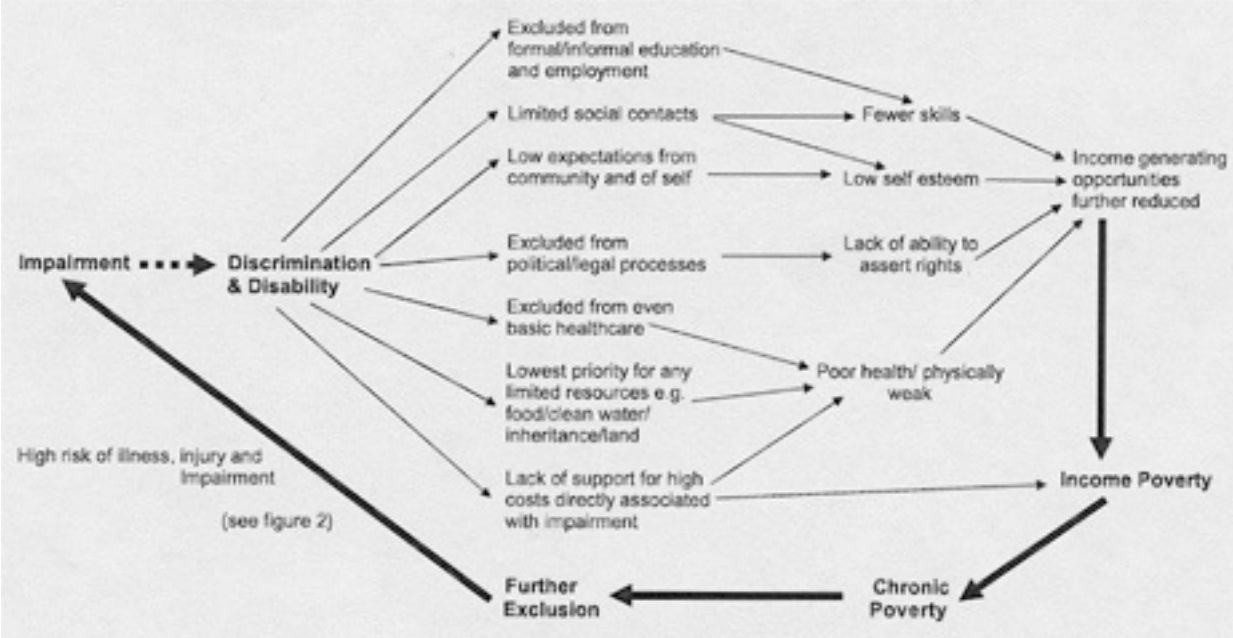
Disability clearly increases vulnerability to poverty, while poverty creates the conditions for increased risk of disability (Emmett, 2006; DFID, 2000; Lott & Bullock, 2001). The poor, already disabled by the structure of society, are doubly disadvantaged if they have or acquire an impairment during their lifetime (Turmusani,2003). Both disability and poverty are the products of societies in which the differences between people are subject to powerful social processes of oppression, marginalisation and adverse inclusion (Turmusani, 2003; Yeo, 2001). Although poverty and disability are closely linked and have a detrimental impact on the overall development, disability has only recently become a focal agenda in development work (Barnes & Mercer, 2004; Coleridge, 2004; Harnois & Gabriel, 2000; McDougall, 2006; Roseveare & Longshaw, 2006)[72]. According to Roseveare & Longshaw (2006, p. 2) mainstreaming disability into development cooperation will involve a "process of assessing the implications for disabled people of any planned action, including legislation, policies, programmes, in all areas and at all levels. It is a strategy for making disabled people's concerns and experiences

71 Discussed further in Chapter 4.

72 Development approaches that see disabled persons as important roleplayers in the economy are increasingly relieving attention in international agencies (ILO, UNESCO, UNICEF, WHO, 2002).

an integral dimension of the design, implementation, monitoring and evaluation of policies and programmes in all political, economic and societal spheres so that disabled people benefit equally and inequality is not perpetuated. The ultimate goal is to achieve disability equality". The goal of inclusion and equalisation of opportunities[73] is indeed ambitious given the inter-relatedness of disability and poverty. To address the former is to address the latter and vice versa. But just how does the interface between poverty and disability work? Figures 2 and 3 depict what Yeo and Moore (2003) call the vicious cycles of poverty and disability.

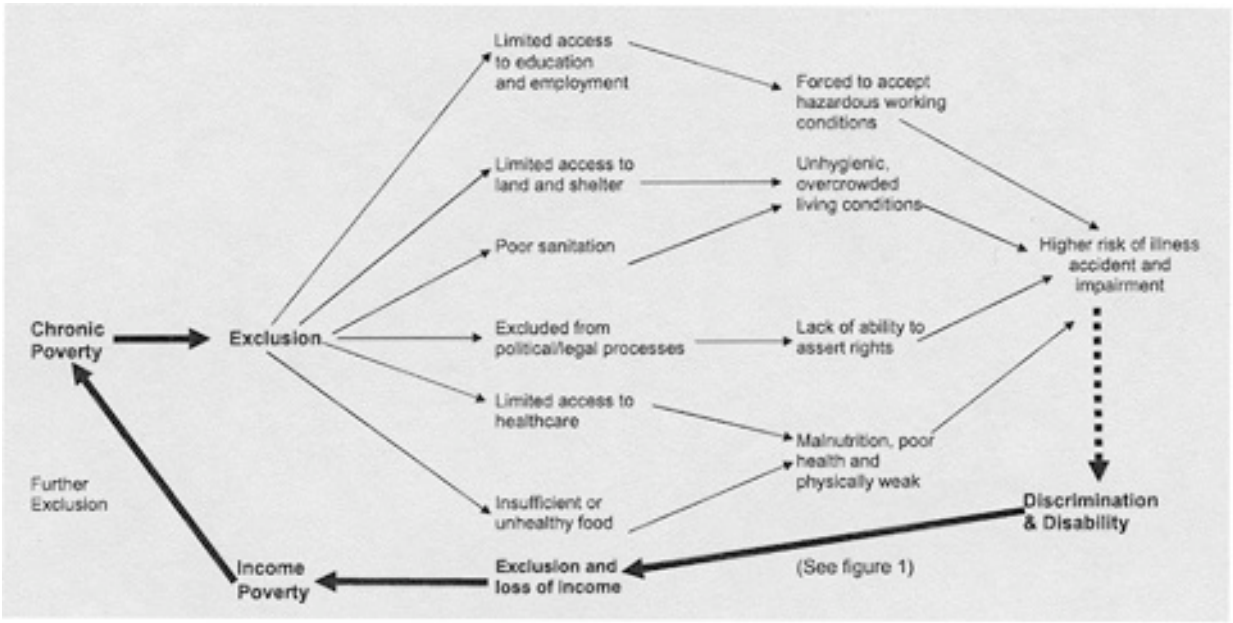
Figure 2: The cycle of disability and poverty
Source: Yeo & Moore, 2003



The vicious cycle of disability and poverty, depicted in Figure 2, moves from impairment to discrimination which in turn feeds into reduced capacity within individuals who in turn have reduced income generating and development opportunities leading to income poverty. This in turn may become intractable due to disabling conditions thereby leading to chronic poverty and setting in motion a cycle of further exclusion that is difficult to break. In Figure 3 the cycle is reversed.

73 Inclusion and equalisation of opportunities refers to how persons with disabilities are taken into account in the design, implementation and evaluation of social safety nets (Mitra, 2005, p.6).

Figure 3: The cycle of poverty and disability
source: Yeo & Moore, 2003



Here chronic poverty is the critical condition leading to exclusion which in turn fuels conditions for higher risk of impairments that lead to discrimination, exclusion and income poverty. Perpetuating the cycle are structural conditions such as malnutrition, lack of basic sanitation, limited access to preventive health services and maternity care, limited knowledge of health practices, inadequate housing, dangerous work conditions, injuries resulting from political and criminal violence, civil conflict and natural disasters. The cycle of poverty and disability is clearly complex, multifaceted and structurally driven. It is likely to differ from country to country, community to community and crucially, from individual to individual. Different types and degrees of disability are also likely to interface differently with poverty; the point being that the cycle itself will vary from context to context.

2.3.8 Poverty and psychiatric disability

In a paper discussing chronic poverty in the urban areas of developing countries, Mitlin (2003) points out that the subject of health is not given sufficient attention, much less so the subject of mental health[74]. Cross national surveys have shown that common mental disorders are about twice as frequent among the poor as among the rich in Brazil, Chile, India and Zimbabwe (Patel et al 1999, cited in WHO, 2001b). In 1990 five of the ten leading causes of

74 Mental health refers to an appropriate balance between the individual, their social group, and the larger environment. These three components combine to promote psychological and social harmony, a sense of well being, self-actualization, and environmental mastery (Schizophrenia Society of Canada Website, 2003).

disability worldwide were psychiatric conditions (unipolar depression, alcohol abuse, bipolar affective disorder, schizophrenia, obsessive compulsive disorder) with projections, at that time, indicating that psychiatric and neurological disorders could increase their share of the total global burden of disease from 10.5 % of the total burden to 15% by 2020 (WHO, 2003a,b; Patel, 2001).

An estimated one member in every four families in the world is living with a serious mental illness (Saraceno & Barbui, 1997). In a review of journals published since 1990, Patel and Kleinman (2003) identified 11 community studies that showed an association between poverty and common mental disorders with low levels of education having the most consistent association. Vulnerability to onset of common mental illnesses such as anxiety and depression was increased with experiences of insecurity, hopelessness, rapid social change and physical ill health (Lund, Breen, Flisher, et.al., 2007). Although mental illness is not responsible for as many deaths as infectious diseases, its global toll perpetuates poverty and disability because it often starts early in life leading to lost potential; may last a lifetime leading to lost quality of life which in turn leads to lost productivity. Mental illness is also associated with considerable stigmatisation and marginalisation leading to lost social participation and human potential (Patel and Kleinman, 2003).

The relationship that exists between mental health and poverty is not widely researched but when it is, the focus is often on how the one causes the other in socioeconomic terms (Beresford, 1996; Wilton, 2004b). Since mental illness generates costs in terms of long-term treatment and lost productivity, a report by the World Health Organisation (WHO, 2002, p. 25) argues that "talking about mental illness means talking about poverty: the two are linked in a vicious circle". The macro economic burden of mental illness of a country may involve direct financial costs (for example social security payouts) or indirect costs (resources lost for example morbidity and mortality loss) (WHO, 2003b). The economic impact of mental illness in developing countries is less qualified than developed countries where loss of productivity in Europe and USA alone accounted for US$120 billion in 1999 through direct costs because of neuropsychiatric disorders (WHO, 2003b). Patel and Kleinman (2003) however point out that most people living in poverty do not necessarily develop mental illness; they are only at greater risk given their marginalisation and deprivation. Table 2, summarised from work done by the World Health Organisation (2001c), lists the macro economic and social costs associated with mental illness.

Table 2: Economic and social costs of mental illness at a societal level
(Source: WHO, 2001b)

ECONOMIC COSTS	SOCIAL COSTS
• Lost production from premature deaths caused by suicide; • Lost production in the short, medium or long term from people with mental illnesses who are unable to work; • Lost productivity from family members caring for the mentally-ill person; • Reduced productivity from people being ill while at work; • Supporting dependents of the mentally ill person; • Direct (transport, treatment and health care costs and other costs directly related to the condition); and • Indirect financial costs of families caring for the mentally-ill person (lost productive labour time, time spent by the caregiver and patient seeking treatment, economic implications of household coping strategies for the household economy.	• Unemployment, alienation, and crime in young people whose childhood problems e.g., depression, behaviour disorder, were not sufficiently well addressed for them to benefit fully from available education; • Costs of accidents by people who are mentally ill, especially dangerous in people like train drivers, airline pilots and factory workers; • Poor cognitive development in the children of mentally ill parents; and • Emotional burden and diminished quality of life for family members leading to vulnerable family systems.

Mental disorders tend to cluster with other disorders; for example depression is a risk factor in heart disease, cancer and alcohol abuse. WHO (2002) estimates that as many as 45 % people with HIV or tuberculosis have a clinical depression which hastens the progression of the disease because people tend not to adhere to treatment regimes due to the functional consequences of a mood disorder. Non compliance is a serious problem because it squanders scarce resources and compounds the effects of poverty for example partial treatment can enable drug resistant HIV and TB strains to proliferate exacerbating the shocks which poor households have to absorb when members become ill. Another example is depressed mothers who tend to produce low birth weight babies. Their children also show slower growth over the first year of life suggesting the potential intergenerational transfer of ill-being (Russell, 2004).

2. 4 DISABILITY

Models of disability include the charity model in which disabled people are seen to be the primary beneficiaries of welfare systems; the medical model which considers disability to be an individual problem that is directly caused by a health condition requiring medical care in the form of treatment or rehabilitation; the social model which considers disability to be a socio-political construct that is not situated in the individual, but rather in the way society treats people who have impairments; and finally, the integrated model, developed by the World Health Organisation (WHO, 2001b). The integrated model of disability, reflected in the International Classification of Functioning, Disability and Health (ICF), sees disability as an

integration of the medical and social models (WHO, 2001a). The biopsychosocial model of disability, advanced by the ICF (WHO, 2001a), bridges the duality between the medical and social models of disability by viewing disability as "the outcome of the interaction between a person's health condition and the context in which the person finds themselves" (Schneider, 2006, p. 9). The context includes both factors external to the person (environmental factors) and those internal to the person (age, sex, education and skill level, coping style, personality). The medical and social models of disability distinguish between impairment and disability, with the former seen as a body function or structure problem that leads to activity limitations and the latter as a social problem caused by systemic processes that restrict the inclusion and participation of disabled people in society (Altman, 2001; Priestley, 2006; WHO, 2001b)[75]. Society is seen to impose disability onto people with impairments making disabled people an oppressed group whose "lived experience of disability is part of the same story of disabling societies" (Priestley, 2001, p. 3). In the case of a mental health condition, impairments may occur at the body function and structure level (for example, neurological or physiological dysfunction leading to hallucinations, thought disorder or loss of drive and motivation) which may in turn lead to activity limitations in domains of function (for example inability to perform self care tasks, be productive at work or relate meaningfully to others) and participation restrictions in various domains of society (for example, experiencing stigma and discrimination related to being 'mentally ill'). Disability activists, in countering the medicalisation of disability, argue that the duality of distinction between the medical and social models of disability is problematic because it fosters the creation of two disparate bodies of knowledge and practice: one pragmatic (dealing with the practical implications of impairment) and the other ideological (contesting systemic, structural responses to difference). For them disability is ultimately a political and not an individual health issue as is proposed by the ICF (Priestley, 2006).

2.4.1 Psychiatric disability and function

The ICF differentiates between three levels of functioning (the body, the person and the societal level) and provides a framework for identifying how facilitators and barriers in the

75 Impairments as defined with respect to physical functional limitation refer to restrictions within the individual caused by a physical, mental or sensory body structure or function problem (Yeo & Moore, 2003, p. 572). Activity limitations refer to restrictions experienced in functional performance as a result of impairment. Participation restrictions refer to physical and attitudinal barriers in the environment that hinder of exude people from access to or inclusion in society (World Health Organisation, 2001a).
Psychiatric impairment, from a medical perspective, is situated in the individual's mental state, that is, in his/her cognitive, affective, conative and socio-behavioural functioning (American Psychiatric Association, 2000). Psychiatric disability, from a social perspective, occurs due to the socio-political barriers, negative attitudes and stigma that people face as a result of their mental illness (Beresford, 2004).

environment promote or impede participation. K and Duncan (2006, p. 301) argue that while the ICF provides a useful universal language for mapping the functioning, disability and health of an individual with a chronic mental illness, it is not "attuned to humans as meaning-making beings". The phenomenology of human functioning, that is, the "personal dimensions of being, doing, becoming and belonging that the doer of the activity attaches to his or her participation in the life they are living" cannot be understood through the application of an objective classification system of disability (ibid, 2006, p. 302). As a classification system, the ICF does not allow for the contradictions, subjectivities, complexities and implications of psychiatric disability.

Viewed from an occupational perspective, the activity limitations and participation restrictions that occur as a result of mental and emotional impairments involve much more than the inability to function, which is what the ICF is concerned with; for example, the extent to which an individual can or cannot perform self-care activities such as bathing and brushing teeth, relating socially or securing a job. K and Duncan (2006, p. 302), argue that activity, as a component of occupation, "may be a communication process whereby thoughts and feelings are expressed non-verbally; the vehicle through which personal identity is expressed and the means whereby human potential is accessed". Psychiatric illness, unlike physical health conditions, might not diminish the individual's practical ability or skill in performing self care activities. What it might do is negatively influence the individual's drive or motivation to perform these daily self-care tasks which, in some psychiatric disorders, may lead to an unkempt or idiocyncratic appearance which contributes, in part, to stigmatisation and prejudice (Isaac and Armat, 1990). The point here is that the occupational performance of humans, irrespective of sickness or health, impairment or disability, adversity or prosperity, enabling or restrictive environments, is imbued with symbolic meaning. What people do and how people act in and on their world is shaped by factors that operate tacitly, unconsciously and/or metaphysically and discursively. The ICF and its classifications and descriptions of human functioning are a product of technology-driven societies intent on logical explanations for phenomenon in order to measure, manage and regulate them. As such, its constructs, significantly influenced by the WHO definition of health, must be applied with due recognition of alternative explanations for the human experience such as those that rely on intuition and on belief in images, dreams and divination to explain and deal with illness, disability and misfortune. The notion of psychiatric disability, in other words, holds significantly different meanings depending on the worldview that is adopted in identifying and explaining the phenomena associated with functional difficulties.

2.4.2 Psychiatric disability and cultural constructions of difference

Swartz (1998) suggests that it is a cultural construction to consider mental health a health as opposed to social, political or cultural issue. He states that "diagnosis in African indigenous healing may be better understood as related to theories of causation of illness rather than simply to taxonomies" (ibid, p. 67). Swartz is referring here to the DSM-IV diagnostic categories[76], but his observations are equally applicable to the ICF. He points out that African ideas about causation of illness (and by inference impairments and disability emanating from such illness) relate to a range of influences in the natural, social, personal, spiritual and political realms and that African explanations for any illness and eventual diagnosis usually rests on four key questions: "Which sickness is it?, How has it happened?, Who or what produced it? and Why did it occur at this moment in this individual?" (ibid., 1998, p. 67). These questions may, in African healing systems, be answered through medical and traditional means. Healing, it is believed, may legitimately be pursued through medication, hospitalisation and other interventions such as psychosocial rehabilitation and psychotherapy or addressed through indigenous practices[77], that is, through the intervention of traditional healers and the shades (McCulloch, 1995). Syncretic treatment seeking behaviours, straddling medical and traditional sources of help, accounted for the double costs incurred by all the research participants during times of relapse and will be discussed again later.

The American Psychiatric Association (APA, 1994, p. xxiv) states that "a clinician who is unfamiliar with the nuances of an individual's cultural frame of reference may incorrectly judge as psychopathology those normal variations of behaviour, belief, or experience that are particular to the individual's culture". The 'why' in people's beliefs is not easily discernable because the answers are, like the thoughts and actions of people everywhere, based on some belief system. Likewise the 'why' of people's occupational performance in surviving poverty and enduring mental illness may be influenced by their worldview, cosmology or life experiences. According to Mkhize (2004, p.38), "metaphysical ontologies are central to traditional African understandings of the world". While he warns that there is no one unifying African metaphysics, the cultural meaning systems and worldviews of Africans do tend to take a hierarchy of beings into consideration when making sense of life events. Holland (2001, p. xiv) states that "because traditional beliefs permeate every aspect of African life,

76 American Psychiatric Association (APA) (1994) Diagnostic and statistical manual of mental disorders. DSM-IV (4th edition) catalogues the range of mental disorders including diagnostic criteria and differential features.

77 Indigenous knowledge is knowledge that is held and used by a people who identify themselves as indigenous to a place based on a combination of cultural distinctiveness and prior territorial occupancy relative to a more recently arrived population with its own distinct and subsequently dominant culture (Guma, 2004).

there is little distinction between secular and sacred, material and spiritual. Where you meet the African, there you will find his religion: in a field harvesting maize; at a funeral ceremony; in the market place. Far from being confined to a church or mosque once a week on a Friday or Sunday, the traditional African's religion embraces his whole environment: his entire time on earth and beyond"[78]. Occupation, considered from this perspective, cannot be categorised into self care, work or leisure; categories that assume time use is linked to functional purposes or practical outcomes[79]. Here occupation is also linked to esoteric meanings that situate the doer as a member of a matrix of beings that operate within different realms of time[80]

2.4.3 Mental illness and belief systems

According to authors such as Russell & Malhotra, (2002) and Mkhize (2004) people embracing an African cosmology believe that their destiny is linked to their actions[81]. They attribute the misfortunes that occur in their lives, including the onset of a mental illness and life circumstances, as caused either by *umkhuhlane* (illness due to natural causes) or *ukufa kwabantu* (diseases of African people), the latter inflicted by the living-dead or by witchcraft because of something they have done or left undone. Personal and household problems, including the onset of *phambana* (mental illness) may be resolved through religion, divination and traditional medicine: one or all of these being the three-fold functions of traditional healers, herbalists, diviners, prophets, priests and sacred kings (Guma, 2004). Considered benevolent mediators of the spirit world and chosen by God to remedy misfortune, the role of these individuals is to keep in touch with the shades and ancestors, identify the cause of misfortune, prescribe remedies, expose evil doers and to provide medicines, potions and rituals to ward off evil, heal an illness or procure prosperity (Mkhize, 2004; Mdleleni, 1990)[82]. Writing about the renewal of moral values in the African renaissance and the difficulties people living in poverty face, Pityana (1999, p. 139) argues that "there is considerable uncertainty about

78 Holland's (2001) writings are not academic. As a journalist she does however provide descriptions of how religion may permeate the occupations of every day life in some cultural contexts. These descriptions correspond with those of Guma (2004) and Helman (2007).

79 See point 2.2.6 above.

80 Harvey and Portland (2004).

81 There are those who are concerned that discussing "an African cosmology" promotes the idea of an essentialised "Africanness" (Swartz, 1998). I use the concept based on the writings of a body of scholarship but without suggesting that there is an essential "Africanness". Also see chapter 4, footnote 22, page 106.

82 Witches, on the other hand, are considered malevolent people (usually female) capable of causing harm by casting a spell or a curse either by leaving their bodies to perform evil deeds or by invoking the living-dead, called uthikoloshe, to do punitive works on their behalf. People 'know' who the witches are in their area or within the family and from time to time such people (who are often mentally ill) are ostracised, attacked or even killed (Pityana, 1999). All the research participants made reference to malevolent forces as contributing factors to their health and social problems.

the future, a precarious existence. The people are unemployed and spend much time worrying about means of life and basic commodities. There is reliance on members of the family or relatives who are either on old-age grants or have jobs to support others. There is a great deal of dependency and fear. The result is that there is a reliance on superstition or religion". Pityana points out that it is widely accepted in African communities that everyone runs the risk of being harmed by a witch at some time or another thereby creating a tacit undercurrent of persecution and jealousy in the community. This problem has been so serious in parts of South Africa that "the Commission on Gender Equality called a special conference to consider approaches to traditional beliefs which result in violations of gender rights" (Pityana, 1999, p. 139). Here disablist oppression is, amongst others, gendered and cosmologically motivated. Understanding psychiatrically disabled people's occupational performance must, given these worldviews, take the metaphysical influences on the ordinary, everyday things that they do into consideration.

According to Cohen (2000), society itself produces mental ill health in that socially created concepts and constructs are used to describe certain mental processes and human behaviours. Mental symptoms then become cultural communications about distress or cultural mechanisms for pursuing occultic purposes in life. A social as opposed to health perspective on psychiatric disability suggests that mental illness and disablist attitudes are linked to knowledge, money, power, prestige and social connections (Cohen 2000). The social function of witchcraft is to apportion blame for misfortune and to ensure that each member of the community has an equal share in its prosperity. It is believed that "the pie is limited and one person's success is always at the expense of another. If an individual prospers beyond the expectations of the others in his community, the successful one may be labelled a witch because he is believed to have augmented personal progress via witchcraft and to have impoverished others in the process" (Holland, 2001, p. 10). Through the discourse of witchcraft, people are reminded not to offend others, be pleasant and unassuming and to resist standing out from a crowd as any enmity or jealousy might set retribution from the unseen realm in motion. So intimately woven into everyday thinking are beliefs about witchcraft that they endorse conformity to the detriment of change creating bondage to fear that may limit the development of human potential. Pityana (1999, p. 139), in discussing morality as the essence of African communal life argues that "rarely do people question the truth claims or validity of this elaborate belief system on which so many depend for ordering of their lives". He suggests that people are trapped in a moral warp which they cannot break out of and that the assumption of community cohesiveness is based on a lack of understanding of how belief

systems influence development[83].

2.4.4 Psychiatric disability and psychodynamic defenses

African cosmology provides one possible explanation for the way in which people make sense of mental illness. Psychoanalytic theory, based on Western[84] interpretations of social behaviour, offers another. In this tradition, behaviour is understood as unconsciously motivated by the dynamic interface between the instinctual, rational and the moral parts of the self (Parker, 2004). Marks (1999), addressing psychodynamic issues in disability, suggests that disablist oppression may be attributed to strong, often unconscious emotional reactions evoked by encountering people with impairments. Patronising, hostile or avoidant responses symbolise unacknowledged, existential anxieties that we all hold in one form or another towards images of people who are perceived to be "broken, damaged, defective and dysfunctional" (Watermeyer, 2006, p. 33). The oppressive construction of disabled people as 'damaged' enables non-disabled people to contain the anxiety that emanates, in the presence of disability, from their own suppressed memories, fears, struggles and losses. These suppressed affects are usually associated with not being 'good enough' or of being 'damaged' in some or other way. Watermeyer (2006, p. 33), writing about the psychodynamics of disability, suggests that "when we cannot manage to consciously 'hold', or tolerate, parts of our emotional experience, we tend to manage the situation by experiencing our feelings through others….without being aware of our actions, we experience our own painful parts as if they reside in, and belong to, others. This allows us the refuge of believing – in our conscious minds – that we do not possess these unwanted and shameful aspects of ourselves". Projected onto disabled (and poor) people then are the parts of society that it would rather disown. Society's responses to disability and poverty are, in other words, often external concretisations of internal patterns of defence organised, in policy form, to manage feelings brought to the surface by the presence of vulnerability in our midst. Development policies, including those pertaining to disability and poverty, may therefore "carry unconscious, and often profoundly influential meanings and motivations" that warrant interrogation to ensure that they do not perpetuate oppression" (ibid, 2006, p. 40). What this implies is that development policy can, paradoxically, become oppressive.

83 Each of the study participants reported fearing retribution through witchcraft either as the cause or the consequence of their illness behaviour. They also attributed their prosperity (or not) to some form of esoteric influence. Whether or not this impacted on their progress over the years is debateable. Their beliefs influenced the meaning and purpose attributed to their everyday activities, tasks and roles ie. their occupations and therefore, it maybe assumed, the trajectory of their agency.

84 See footnote 38.

2.4.5 Psychiatric disability and mental health policy

Turmusani (2003) suggests that in developing countries the key issue for disabled people living in poverty is meeting their basic survival needs. This is in contrast to some developed countries where people with disabilities are more concerned with issues of equality and anti-discrimination legislation. South Africa is particularly progressive in its legislative and policy approach to disability. In fact, it has one of the most active and visionary disability movements in the world that has secured the integration of disability within government structures including the Constitution and the South African Human Rights Commission (Office of the Deputy President, 1997; Watermeyer, Swartz, Lorenzo et al., 2006). The challenge is "up to the disabled community along with other role players to make the Constitution work for rapid change and an inclusive and equitable society for all" (Nhlapo, Watermeyer & Schneider, 2006, p. 106).

Despite progressive disability policies, things are not yet working smoothly on the ground people with mental illness (Lund, Kleintjies, Campbell-Hall, et.al., 2008). For example, MacGregor (2006) highlights the ambiguity of grant negotiations between doctors and 'clients' at psychiatry clinics in Khayelitsha. Having "iinerves" embodies the distress associated with harsh living circumstances and is often deemed by applicants to warrant a grant. Changes in grant criteria influence people's experience of illness, especially the way in which mental illness is conceptualised and presented to secure social assistance. MacGregor (2002; 2006) found that illness narratives were a multilayered confluence of indigenous explanations, Christianity, biomedicine, the media and references to national ideologies of justice and rights. Illness narratives merged subjective experiences of social suffering into mental distress that applicants felt warranted a grant in accordance with their interpretation of government promises of social security. She states that "national level policy ambiguity is mirrored in the clinic politics of grant negotiation in particular in the way in which local expectations of state welfare provision in the form of grant receipts were not often met in practice. In the decision-making of the doctor, people encountered a reflection of the neo-liberal ideas representative of the other face of state discourse about grants" (ibid, 2006, p. 49).

MacGregor (2006) also argues that "struggle" discourses that the State has inherited from its liberation movement past imply commitment to restorative justice. This involves expectations of provisioning for 'the people' within a human rights framework through monetary payments handed out to identified victims of apartheid. Against this backdrop

as well as the much publicised disability rights agenda, applicants have come to assume eligibility for social grants as compensation for enduring suffering that causes 'iinerves'. However, eligibility is regulated within a medicalised framework that discerns the impact of impairment on function. Disability grants become lodged in the disjunctions between a local political discourse about the genesis of illness, a justice ideology and the lack of attention to structural problems that affect well-being. These are indeed extraordinary challenges for the government, service providers, development practitioners and disability activists as they seek to interrupt, and ideally break, the vicious cycle of poverty and disability.

Two particular paradoxes are at play. Firstly disabled persons, empowered by a progressive policy framework to achieve equal opportunities and social inclusion, are simultaneously disempowered by poverty. Often the sole provider of the household through the disability grant, the disabled person becomes torn between adopting an illness or disability identity as a survival strategy and adopting an alternative identity as a survivor in pursuit of personal development (Duncan, Eidelman, Gouws et al, 2006). Secondly, people's beliefs about interventions aimed at addressing their health conditions are influenced by the medical model and by traditional healing practices in which the recipient adopts a passive role in pursuit of healing and wellness. For example, medicine is prescribed by an 'expert' and taken by the 'patient'; an operation is performed by a doctor or a ritual is performed by a traditional healer. The 'problem' is 'sorted out' by someone else's (usually perceived as more powerful and knowledgeable) actions. This is not how occupational therapy, community based rehabilitation and development practice works. Here the locus of control has to be assumed by the disabled (and poor) person him/herself resulting in active pursuit of solutions to the problems of living. Professionals and development practitioners act as expert resources, enabling advisors and collaborating partners. As 'passive' recipients of social security, disabled people may become trapped not only by the barriers imposed by chronic poverty and social injustice, but also by the belief that some external agent or expert must 'fix' the problem. These two paradoxes pose particular challenges for mental health occupational therapy services in the context of chronic poverty.

2.5 CONCLUSION

This chapter has reviewed literature relevant to human occupation in the context of poverty and psychiatric disability. Philosophical contestations in the way occupation is defined and viewed in occupational therapy and occupational science were introduced. Definitions and descriptions of occupation were presented in relation to its form, function and process. A rationale was provided for using the basic elements of occupation as the primary conceptual

framework for this study. Four categories of occupation that structure and pattern daily life were introduced and applied to the study context: necessary, committed, contracted and discretionary. This was followed by a summary of approaches to poverty indicating how each approach seeks to address the needs of people living under disabling socioeconomic conditions in different but complementary ways. A range of perspectives on psychiatric disability and poverty were introduced arguing that while the distinctions made between impairment and disability are helpful in identifying different domains of knowledge and expertise, such dualistic constructions tend not to exist in African cosmology. It pointed out that any attempt at understanding the occupational performance of individuals and households surviving chronic poverty and mental illness in South Africa must be mediated by an appreciation of people's worldview and indigenous knowledge systems. The cycle between poverty and disability was briefly discussed highlighting the reciprocal relationship between mental state impairment, psychiatric disability and the structural barriers that disabled people face in accessing development opportunities. It argued for the considered application of diagnostic and disability taxonomies suggesting that human functioning is phenomenological (as opposed to static, objective and measurable) and subject to a range of intrinsic variables and extrinsic discursive forces including local belief systems and cultural practices. The chapter has sought to highlight two main points. Firstly, occupation is dialogical ie. it not only provides the means through which people can achieve their needs and goals as actors in their material and social world, it is also shaped by the material and social world in which it is performed. Secondly, neither disability nor poverty can be homogenised and essentialised; there is no universal experience of being mentally ill, disabled or poor. In conditions of pervasive deprivation and marginalisation poverty and disability are two sides of the same coin: to be poor is to be disabled and to be disabled is to be poor. The next chapter discusses the study methodology.

CHAPTER THREE: METHODOLOGY

3.1 INTRODUCTION

The first part of this chapter briefly describes the methodology of Phase 1 of the larger PDO Study because it laid the foundation for Phase 2 on which this dissertation is based[1]. Phase 1 focussed on identifying appropriate geographical localities, demarcating the study population, gaining community entry and framing the sampling criteria. The second part of the chapter details the methodology of Phase 2 and describes the theoretical orientation that was adopted, justifies the use of case study method, and details the use of interpretive data collection and analysis. The third part of the chapter focuses on issues of power, the use of reflexivity as a methodological stance and how socially responsible research ethics were applied to promote the interests of the research participants.

3.2 PART ONE: PDO STUDY PHASE 1: METHODOLOGY

The information presented here is summarised from the Phase 1 study report by Watson (2005) who was the PDO project research fund manager and leader. Table 3 describes the PDO study Phase 1 research timeline, process and activities.

Table 3: PDO Study Phase 1: research timeline, process and activities

TIMELINE	PROCESS	ACTIVITIES
2003	Watson (2005) is awarded a grant by SALDRU[1], UCT	**DOCUMENT SURVEY OF POPULATION IN CAPE METROPOLE** (Khayelitsha Site B & Browns Farm identified as target areas meeting inclusion criteria) ↓
	Commence PDO study ↓	**COMMUNITY ENTRY** Association for Physically Disabled; Cape Mental Health Society[2]; clinics at Provincial Government Day Hospital; community rehabilitation workers associated with SACLA[3]
2003-2004	SAMPLING ↓	↓
	DATA GATHERING (descriptive & quantitative) ↓	**DEMOGRAPHIC SURVEY OF 32 SAMPLED HOUSEHOLDS** (16 with physically disabled member, 16 with psychiatrically disabled member) (using semi-structured interviews, focus groups and questionnaires) ↓
2005	DATA PROCESSING and DISSEMINATION	**DATA ANALYSIS, INTERPRETATION & REPORTING (Watson, 2005)**

Table 3: Explanation:

1. Mellon Grant linked to South African Labour Development & Research Unit, Department of Economics, University of Cape Town
2. Preliminary discussions and advice on community entry and sampling
3. SACLA: South African Christian Leadership Assembly

1 See Chapter 1, page 4. As a member of the PDO study research team I contributed to the design and execution of certain components of Phase 1.

3.2.1 PDO Study Phase 1: research questions

Using mixed methodology, the PDO study Phase 1 research questions aimed to elicit information on the demographics of 32 households in terms of their socio-economic, health/ disability and occupational profiles. The demographic information of each case study in this dissertation was gathered during Phase 1[2]. Table 4 provides an overview of and rationale for the research questions and methods used in Phase 1.

Table 4: PDO Study Phase 1: research questions

PHASE	RESEARCH QUESTIONS	METHODS	RATIONALE
1	- What are the socio-economic demographics of households in the poorest suburb(s) of the Cape Metropole? - What makes and keeps the sampled household poor? - What do members of the sampled household do to cope with their life circumstances?	Document analysis Cape Town Equity Gauge Semi-structured interviews Focus groups	To provide quantitative, descriptive data as background to in-depth case studies in Phase 2 (psychiatric disability) & Phase 3 (physical disability). [Phase 2 is the basis of this dissertation]

3.2.2 Identifying the PDO study population and locality

Based on information gathered from a range of national and local surveys, in particular the Cape Town Equity Gauge Project, we proceeded to identify suitable sites for our work[3]. The purpose of Phase 1 was to support the qualitative PDO case studies in Phases 2 and 3 with demographic information about the study population. The Cape Town Equity Gauge Project covered the health districts of Khayelitsha (32 suburbs) and Nyanga (23 suburbs), so these areas were pre-selected for the purposes of the PDO study. It was necessary to find the most poorly resourced and impoverished communities or suburbs within each district. Two processes were used to do this. The first process identified suburbs that included very poor people and disabled residents using two arbitrary inclusion criteria: firstly, more than 50% of the households living below the poverty line (pre-determined at R1000 (+/- $100) per month by the Cape Town Equity Gauge Project) and secondly, more than 50 people in the area unemployed due to a reported disability. Sixteen suburbs in the Khayelitsha Health District and nineteen in the Nyanga Health District met the first criteria while seven suburbs in the Khayelitsha Health District and seven in the Nyanga Health District met the second criterion.

2 Contributing information towards achieving the first study objective, see Chapter 1, page 13.

3 The research team consisted of project leader Watson (Division of Occupational Therapy, University of Cape Town); two doctoral students (myself focusing on psychiatric disability and another occupational therapist focusing on physical disability); an occupational therapist research assistant and a number of community rehabilitation workers who acted as cultural brokers, interpreters and research assistants.

Ten suburbs met both of these population criteria[4]. Each of the ten suburbs in 2003 had populations of over 2000 people aged between fifteen and fifty years. This was determined to ensure that even if only 5% of the population were disabled, 100 disabled people of working age would be available to be considered for inclusion in the PDO study[5].

The second process involved consideration of the socio-economic data in the ten identified population suburbs[6]. Differences between the suburbs were highlighted for consideration. The Cape Town Equity Gauge data were again used to identify the four most poorly resourced suburbs that could be considered as exemplary presentations of the problems we set out to study[7]. The prevalence of disability was determined by identifying areas in which the highest number of social grants were issued. Figures for the Care Dependency Grant were not supplied excepting for Khayelitsha Site B where 201 grants were issued in March 2003[8]. No disaggregated data on psychiatric or physical disability was available, so these figures were included as a general indicator of disability prevalence.

3.2.3 PDO Study Phase 1: sample

Having identified the most poorly resourced suburbs in which the sample population resided, we set out to implement Phase 1 of the PDO study. The following inclusion criteria were used for participant selection based on the principles of purposive and maximum variation sampling (Creswell, 1998; de Poy & Gitlin,1994).

- *Size of household: at least three people, one of whom was a disabled person*

The average size of a household in Khayelitsha in 2002 was 5.6 persons (City of Tygerberg, 2002). The criterion of three people or more per household was based on the decision to include at least a disabled person, a carer or the person closest to the disabled person, and one other. One of these three needed to be the head of the household[9]. Six households were excluded from the study because they did not meet these criteria. In four of the excluded households

4 Harare, Macassar, Khayelitsha Site B, Khayelitsha Site C, T.Vilakazi, Brown's Farm, Lower Crossroads, Nyanga, KTC and Old Crossroads.

5 Physical, psychiatric and sensory disabilities were included.

6 The number of residents, the source of household energy and water supply, the household income, levels of employment and education in the area, and the types of dwellings were compared.

7 One suburb was in Khayelitsha (Site B), and three were in Nyanga (Brown's Farm, KTC and Lower Crossroads).

8 Personal communication with the Khayelitsha District Officer at that time

9 See Chapter 1, footnote 6, page 2 for definition of household.

the disabled person that was identified by community health workers had a health condition that did not impede their functioning for example controlled diabetes. Two disabled people lived alone and therefore did not meet the adopted definition of a household.

- *Income: not more than R740 per month for every adult or adult equivalent*[10]

This was the amount of the social security (disability) grant in 2004. It is not a generally accepted standard of poverty measurement, but was useful because it introduced a financial element into the general description of poverty. The poverty line used by the Equity Gauge Project in 2003 was R1000 per month (approx. $100).

- *Duration of poverty: at least three years*

The intention here was to determine how long someone had been poor and how severe this poverty had been[11]. Poverty in South Africa is exacerbated by the apartheid legacy of skewed resource allocation, inferior education, labour migration, limited employment opportunities and inadequate social support services[12]. The duration of living in the identified suburbs, level of education, type and condition of household assets and facilities including furnishings, equipment, type of dwelling and sources of income including the type and number of grants[13] were used as indicators of the extent and duration of poverty[14].

- *Capability: the freedom to be and do the things that the person wanted and chose to do*

Sen's (1999, p. 6) work on capabilities and entitlements stresses that "what counts is not what (poor) people possess, but what it enables them to do". The lack of material assets and commodities (for example furniture, appliances, a bicycle or trolley to transport goods) was not confused with the lack of capabilities to meet cultural conventions, participate in social

10 Adult equivalent is two children under 15 years of age.

11 Different researchers suggest different time periods as characteristic of chronic poverty (the suggested time is five years), usually taken to mean that the household or individual remains beneath the prevailing poverty line for all or virtually all of the identified period (Aliber, 2003; Hulme et al., 2001).

12 According to Aliber (2003) this combination is more than sufficient to make people chronically poor; a combination descriptive of the population in the identified suburbs.

13 Lund (2004), conducting research in KwaZulu Natal, reports that many South African households in certain sections of the population survive solely on social security grants.

14 See Appendix 5 for Phase 1 demographic survey and interview guide

activities, and retain self-respect. Capability deprivation[15] as a sampling criterion considered reported barriers to economic and social participation, including restrictions to occupational development for example inability to make use of opportunities to attend skills training due to lack of resources (human and financial).

Finding households that met the inclusion criteria was very difficult and happened primarily through snowballing technique[16]. Maximum variation sampling was indicated in terms of age, gender, type and history of disability, residential locality, and socio-economic and family history. Approximately half of the sample had to have a disabling physical health condition or impairment, while the other half had to have a history of severe mental illness. The majority of people interviewed lived in Site B and Brown's Farm[17].

3.2.4 PDO Study Phase 1: gaining access

An attempt to find disabled people via a community based service organisation was not fruitful while approaching street committees was not possible because they did not exist in all the areas where we wanted to work. The health or social service route was avoided in order to eliminate bias. The two Disabled Peoples' Organisations (DPOs) [18], that we approached were unable to help us because of their commitment to member anonymity. Eventually, through a process of meeting with local support groups associated with APD and CMH and explaining our intentions, we identified people who were willing to talk with us. They wanted to know how we intended to help them. We explained that our intention was to promote understanding of disability and poverty and to make meaningful service proposals including feedback to the various constituencies[19]. We were very clear that we would not be offering a professional service but would instead refer any problems that we identified through the appropriate channels. We did not disclose that we intended to give food-packs[20] to participants, for fear of raising expectations and introducing bias. Two community rehabilitation workers (CRWs) who were acquainted with disabled residents in the areas were appointed to the project and

15 The concept of capability deprivation (Sen, 1999) focuses on poverty as a limitation on the freedom to 'be' and to 'do'. The PDO Phase 1 questionnaire elicited information on perceived barriers that informants faced in realising their aspirations through occupation. See Appendix 5.

16 This technique introduced potential bias and therefore reduced the generalisability of the findings.

17 See footnote 7. The number of people selected from KTC and Lower Crossroads was unfortunately limited because not all the people that we were introduced to met the criteria or offered the personal characteristics that we required.

18 The Western Cape branch of the Association for the Physically Disabled (APD) and Cape Mental Health (CMH).

19 We provided each organisation with a copy of the Phase 1 report (Watson, 2005) and also addressed consumer representative groups about the findings.

20 A food pack (valued at R30) was given to each household as a token of appreciation after each interview.

acted as community brokers and translators.

3.2.5 PDO Study Phase 1: demographic interviews and focus groups

The demographic interview guide, compiled, then piloted and modified before being implemented, was designed to collect personal, socio-economic and occupational information from the head of the household[21]. Checking the eligibility criteria preceded the interview. At this stage it was necessary to make a visual assessment of the health condition or impairment of the disabled person[22]. The interviews all followed the same format and were conducted by the research assistant who also provided simultaneous translation for the researchers' benefit. The researcher was free to look around the dwelling and to observe the interviewee while s/he was being interviewed. Sketches were made of all the dwellings as a memory aid and the household contents noted. When the demographic interview was finished, we asked the head of household if s/he would be prepared to attend a focus group to talk together with other heads of household about some of the things that we had covered in the interview. If they were willing, further arrangements were made. Three focus groups were held; two in Brown's Farm and the third in Khayelitsha Site B. Appendix 4 contains a summary of selected information from the Phase 1 demographic survey and focus group findings. It provides background to Phase 2 of the PDO study which was the focus of this dissertation.

3.3 PART TWO: PDO STUDY PHASE 2: METHODOLOGY

I commenced prolonged engagement[23] early in 2004 with five case study households that were purposively selected from the PDO Phase 1 sample of 32 households. My aim was to gain an in-depth qualitative understanding of occupation in the context of poverty and psychiatric disability in each of these households separately and to explore commonalities across the cases with reference to costs, coping strategies[24] and the interface of these with occupation. Table 5 summarises the PDO study Phase 2 research timeline, process and activities.

21 See Appendix 5.

22 We were not able to access health records at clinics for two reasons: in some cases there were no records available and we were not granted ethics approval to access records directly from provincial health services. We did interview clinic staff. Diagnoses were therefore identified through our observation and clinical experience including reference to the person's clinic card (if available).

23 Regular visits (approximately two-three month intervals) over a period of three years. Some visits were scheduled as interview times while others were ad hoc and focussed on observation and maintaining the research relationship. I also slept over in an informal dwelling for participant observation purposes.

24 Coping strategies are a set of actions that aim to manage the costs of an event or process that threatens the welfare of some or all of the household members. Coping strategies seek to sustain the economic viability and sustainability of the household (Sauerborn, Adams & Hein, 1996).

Table 5: PDO Study Phase 2: research timeline, process and activities

2004 **2005** **2006** **2006-2007** **2009**	**PHASE 2** PURPOSIVE SAMPLING ↓ DATA GATHERING (qualitative) ↻ ↺ DATA PROCESSING and DISSEMINATION	**SELECT FIVE CASE STUDY HOUSEHOLDS** (from Phase 1 sample in which 16 households had a psychiatrically disabled member) ↓ **PROLONGED, ITERATIVE ENGAGEMENT** (in-depth interviews and observations: approximately 1-3 visits every 2-3 months; 12-15 hours per household) ↻ ↺ **ITERATIVE DATA ANALYSIS AND INTERPRETATION** ↻ ↺ **REPORTING** (submit D Phil dissertation; present papers at various conferences)
2008-2010	PHASES 3-5 of PDO study	**INTEGRATE PHASES 1-3 & REPLICATE IN RURAL EASTERN CAPE** (not addressed in this dissertation)

3.3.1 Research stance

Issues of power between researchers and participants inevitably arise and warrant consideration throughout the research process (Martin, 1996). Influencing the research stance in this study were issues of power arising between the researcher as a middle class, middle aged, white Afrikaner woman and black African, isiXhosa-speaking individuals with a history of serious mental illness living in chronically poor households on the margins of a deeply divided society[25]. I do not speak isiXhosa and therefore felt like, and was probably perceived as, an intrusive outsider[26]. These and other differences influenced the research stance that was adopted. Doucet and Mauthner (2002), writing from a feminist perspective about the ethical challenges of social inquiry, suggest that knowing responsibly involves linking ethics, methods, methodologies and epistemologies in explicit terms. For these authors, knowing well and responsibly depends on being as accountable and transparent as is reasonably possible about "the epistemological, ontological, theoretical and personal assumptions that inform our research generally, and our analytic and interpretive processes specifically" (Doucet & Mauthner, 2002, p. 125). With this in mind, I endeavoured to adopt a

25 According to Parker (2005) wilful ignorance about the political in research is not merely unethical; it may mean complicity with injustice. The disparities between class and race in South Africa and other legacies of apartheid were briefly addressed in Chapter 1.

26 I speak a central African patois based on the Nguni language group and could therefore follow some isiXhosa conversations. One research informant said "since she (participant) became ill she does not want anything to do with uMulungu (white people)... I reckon that when she sees uMulungu she thinks they have come to fetch her, maybe they want to put her in hospital...". By inference I was perceived to have the power to place her in hospital against her will because I was white.

reflexive stance[27] throughout the study. In particular, my response was to engage reflexively (Doucet & Mauthner, 2002; Parker, 2005; Swartz, Gibson & Gelman, 2002) with the cross cultural disjunctions encountered on every visit[28].

Foucault (1980) suggests that a discourse of difference is the consequence of Western experiences under imperialism. He suggests that race, gender and class distinctions and hierarchies of power based on these distinctions are so deeply encoded in Western languages, cultural archives and research paradigms that the West itself (and by inference professionals like myself schooled in Western thinking about human occupation) cannot discern the tacit 'rules of practice' that inform our stances towards people whom we perceive to be different from ourselves. We operate within and through such rules of practice and therefore take them for granted[29]. How could I discover, as an outsider, what the research participants counted as 'real' in terms of their occupations when I was bound by the rules of systematised knowledge required by scientific and academic debate in the West? It was not my intention to answer this question during the study but to hold it up as a reminder of the task at hand which was to remain as reflexive as possible about the interpersonal dynamics operating during the research process and about the assumptions I held about the impact of class, race and privilege occupation.

27 Reflexivity is "a way of working with subjectivity in such a way that we are able to break out of the self referential circle that characterizes most academic work" (Parker, 2005, p.25.). He proposes four dimensions that must be interrogated regularly throughout the research process to break a self referential circle of thinking: making first person confessions (assumptions and biases etc.); clarifying second person social positions (gender, race etc); being aware of third person theorizing (adopting a critical perspective towards taken for granted ideas) and a fourth dimension of crafting a report that foregrounds instances of disjunction (for example see Glimpses of a research event below).

28 I include a vignette of an interview event to demonstrate this stance. See point 3.3. 7.1 below.

29 In similar vein Smith (1999, p.47), writing about decolonising research and indigenous peoples calls the mind trained by Western notions of reality a "force-field that unconsciously screens out competing and oppositional discourses". She argues that Western theories and rules of research "are underpinned by a cultural system of classification and representation, by views of human nature, human morality and virtue, by conceptions of time and space, by conceptions of gender and race. Ideas about these things help determine what counts as real" (*ibid*, 1999, p.44). I trained as an occupational therapist in an exclusively white training centre at the Hendrik Verwoerd Hospital in Pretoria during the apartheid era in the early 1970's. We did our clinical training in racially segregated facilities and followed a curriculum that was informed by British and European standards of practice. Although much progress has been made in transforming the racial and gender profile of the profession since the first democratic elections in 1994, the development of indigenous interpretations of professional constructs and practice remains a big challenge.

3.3.2 Research approaches

Table 6 depicts the research approaches that were used to achieve the study aim.

Table 6: PDO Study Phase 2: research approaches

ELEMENT	STANCE
Fields of inquiry	Occupational therapy and occupational science
Approach	Qualitative
Theoretical orientation	Interpretivist
Conceptual frame	Basics of an occupation (Nelson and Jepson-Thomas, 2003)
Methodology	Case study
Methods	In-depth interviews, observation, fieldnotes, focus group, participant diary (one).

Pre-determined by the rationale for the larger PDO study combination of topics, the fields of inquiry were addressed in Chapters 1 and 2. A naturalistic, qualitative approach was adopted because it enabled multiple perspectives of participant's subjectivities and experiences to emerge through interpretation of their narratives (Devereux & Hoddinott, 1993). An interpretive theoretical orientation was indicated because it allowed for uncertainty in the process of generating knowledge (Geertz,1979). Interpretivism operates on the premise that the generation of knowledge has consequences, especially in naturalistic contexts where research findings cannot be seen as certain; everything is open to questioning and multiple explanations. According to Henning, van Rensburg & Smit (2002, p. 20) "interpretive knowledge is dispersed and distributed. The researcher has to look at different places and at different things to understand a phenomenon. That is why interpretivist research is a communal process, informed by participating practitioners and scrutinised and/or endorsed by others. Phenomena and events are understood through mental processes of interpretation which are influenced by and interact with social contexts … Interpretivists do not seek universal laws or predictive generalisations; only to develop understanding of individual cases". Understanding that emerged from the research process and the data analysis was therefore based on a number of methodological checks and balances that were used to interpret findings[30].

3.3.3 Research conceptual frame

A conceptual frame provides a focal theoretical structure for working methodologically and analytically with data. The basics of an occupation (Nelson and Jepson-Thomas, 2003, p.111),

30 To this end, I held regular debriefing sessions with research assistants; co-analysed data with experienced mental health practitioners familiar with the context; followed through on member checks; kept a fieldwork diary; triangulated within and across case findings and confirmed these with reference to literature and held discussions about the findings with African academics familiar with the isiXhosa culture and peri-urban settlements. I also attended a series of UCT summer school lectures on indigenous knowledge systems (presented by and based on doctoral research by Guma, 2004) to familiarize myself with the Xhosa culture.

discussed in Chapter 2 (see page 20-21), was adapted as a conceptual frame to guide data gathering, analysis, interpretation and reporting. This particular conceptualisation of the basics of an occupation was considered suitable because it is not overtly orientated towards therapeutic intervention. The primary research foci emanating from this framework and informing the structure of observations and interviews were: the actor(s), the action(s), the motive(s), the outcome(s) and the context.

3.3.4 Case study methodology

Case study methodology was chosen because it enabled learning about a specific event (occupation) and/or person (disabled informant and/or key household member) as a bounded system to occur[31]. According to Stake (1995) a case is an integrated system, a 'functioning specific' that is purposive, has working parts, identifiable features and patterned behaviour that can easily be recognised as belonging to a bounded whole. Whereas a case is something that functions and operates as an entity, the focus of the study is the observations, descriptions and interpretations of these operations, in this instance, the occupation(s) of participants. Flyvbjerg (2004, p. 421) suggests that "context-dependent knowledge and experience are at the very heart of expert activity. Such knowledge and expertise also lie at the centre of case study as a research and teaching method; or to put it more generally still as a method of learning". A methodology that would promote learning was indicated given the paucity of literature on the study topics[32]. In short, the case study in this dissertation refers to the bounded system represented by each of the five informants in the context of their households.

Stake (1994) differentiates between three types of cases: intrinsic, instrumental and collective. The intrinsic case study is selected because of its ordinariness; the case is in and of itself interesting because it has a particular story to reveal. Its representivity of other cases or its condusiveness to building theory is not a primary consideration. As Stake (1994, p. 237) puts it, "the intrinsic case study is undertaken because one wants better understanding of this particular case". The intrinsic case studied in this research was the index person in

31 Case study methodology also allowed deeper understanding of the constructs within the basics of occupation (Nelson and Jepson-Thomas, 2003) to occur. As Stake (1994, p. 245) advises, "the utility of case research to practitioners and policy makers is its extension of experience. The methods of qualitative case study are largely the methods of disciplining personal and particularised experience".

32 The major conceptual responsibilities of the qualitative case researcher is to conceptualise the object/ event of study (occupation); select phenomena or issues to emphasise (varies from case to case); identify patterns of data so as to enrich understanding of foreshadowed issues; triangulate observations through categorical aggregation of findings, and finally, to develop assertions about the case to promote learning about the object of the study.

each household; the individual with a history of mental illness who, as an occupational being, performed roles, activities and tasks in particular ways that contributed (or not) to the household's livelihood. I was interested in understanding the disabled person's intrinsic world; that is, his/her story as an occupational being living with the vulnerabilities imposed by mental illness in an impoverished, disabling context. In re-telling the intrinsic story, I wanted to describe the index person's perspectives and personal interpretations of occupation in sufficient detail for the reader to arrive at a deeper appreciation of the foreshadowed issues[33]. Due to length constraints only one intrinsic case is presented in this research report as an exemplar of the findings.

The instrumental case study is "a particular case that is examined to provide insight into an issue or refinement of theory" (ibid, 1994, p237). From an instrumental perspective, the primary issue studied in each intrinsic case was the particularities of occupation as a means for securing income. The aim was to describe occupation in sufficient detail so that aspects of the theory of occupation could be explicated. This was made possible by asking: what is this case of occupation a case of? Dorcas's primary contracted occupation of selling second hand clothes is used as an exemplar instrumental case study. The collective case study refers to the study of several cases jointly (Stake, 1994). It is not the study of the collective, but rather of the instrumental study extended to several cases in order to gain better understanding of a process. While a collective case study was not indicated given the complexity of the construct of occupation, a cross-case analysis was used to identify the costs of psychiatric disability to poor households in relation to the illness behaviour and occupational performance of the disabled person and to identify common strategies that were used within everyday occupations by the disabled person and his/her household to deal with poverty and psychiatric disability[34].

Case study methodology is not without its detractors (Dogan & Pelassy 1990; Diamond, 1996, both cited in Flyvbjerg, 2004). The main contestation is that the knowledge claims of case studies are based on evidence that is subjective, anecdotal and unrepresentative.

33 Foreshadowed issues were identified in relation to the research objectives: profiling each of the five index disabled informants in the context of their household structures with reference to their occupational and health history; the basics of their (self identified) primary income generating occupation (form, developmental structure, meaning and purpose and performance); the costs associated with psychiatric disability and the strategies used to offset these costs in relation to the occupational performance of the disabled and household members.

34 A focus on the cost burden of psychiatric disability was indicated because of its implications for poverty while a focus on strategies for dealing with costs was indicated because of its implications for occupational performance.

Findings cannot be generalised. However, Flyvbjerg (2004) points to the benefits of case study methodology. He argues that case studies focus on 'little things'; a discreet and apparently insignificant truth, will, when closely examined, reveal itself to be pregnant with metaphors and general significance. These 'little things' can contradict and thereby challenge preconceived ideas or confirm existing theories, in this instance human occupation and occupational performance. Flyvbjerg (2004, p. 429) states that "the case study contains no greater bias towards verification of the researchers preconceived notions than other methods of inquiry. On the contrary, experience indicates that the case study contains a greater bias towards falsification of preconceived notions than towards verification". Russell (2005, p. 288) also argues in favour of case study methodology in health economics saying that "just as clinical sciences can use cases to understand disease causation, so social science can use cases to understand and build theory about poverty causation … it is one thing to identify vulnerable groups and their characteristics, and another to understand the mechanisms that have made them vulnerable and how these operate within households to 'filter' policy efforts and impact". Although the findings of this study cannot be generalised, valuable insights were gained about human occupation that may be applied to mental health occupational therapy practice.

3.3.5 Sampling

Phase 1 created a sampling frame for Phase 2. Five cases from amongst sixteen of the thirty two households that met the inclusion criteria for Phase1 of the PDO study were identified[35]. Selection was based on those cases from which we could learn the most because they contained critical features of relevance to the Phase 2 research questions. Understanding and gaining the best possible explanation for the critical phenomena under investigation depended on "choosing cases well, on choosing one or a small number of exemplars of the issues raised by the research questions" (Stake, 1994, p. 243). Appreciating Stake's (1994, p. 243) point that "potential for learning is a different and sometimes superior criterion to representativeness", we selected five cases that were logistically accessible and offered both variety across attributes (diagnosis, gender, age, household size) and, primarily, opportunity to learn about occupation in the context of enduring poverty and mental illness[36]. Cases had to agree to be bounded by time (prolonged engagement), be bounded by place (localities meeting inclusion criteria for poverty) and by system (poor households with one member

35 See Table 3, page 60

36 Although a single case can be studied in great depth, case study researchers recommend a sample size of four (Creswell, 1998). Five cases were selected to create cross-case comparisons and the beginnings of isolation of crucial variables.

who had a psychiatric disability) [37].

3.3.6 Introducing the research participants

Table 7 provides a profile of the research participants when the study commenced in 2004 with reference to their age, gender, marital status, medical diagnosis, self diagnosis (based on cultural explanations for particular personal experiences), number of admissions to a psychiatric hospital, level of education, locality, access to social security, household size and primary source(s) of income.

TABLE 7: Profile of research participants[38]

Name	Vuzi	Siyanda	Sesetu	Fuzile	Dorcas
Household name	Bekwa	Kamana	Nombewu	Sojolo	Somngesi
Age	38	30	25	50	55
Gender	Male	Male	Female	Male	Female
Marital status	Single	Single	Married , 3 children	Married, 4 children	Divorced, 2 children
Medical diagnosis (see Appendix 3 for more information on medical diagnosis)	Bipolar mood disorder & substance abuse induced psychosis	Schizophrenia	Neuropsychiatric disorder with epilepsy (not a mental illness)	Organic brain disorder with alcohol abuse Stab wound to the head, mild hemiplegia	Bipolar mood disorder
Self diagnosis (see Appendix 2 for orthography)	Ndine iinerves Phambana Ukugula ngengqondo Ukuphazamiseka ngengqondo	Uyacinga kakhulu Inkenkqe Phambana Ukugula ngengqondo Ukuphazimiseka ngengqondo	Idliso Amafufunyane Ukuthakatha	Ukugula ngengqondo Ukuphazamiseko ngengqondo Andikho zingqondweni	Phambene Ukugula ngengqondo Ukuphasemiseko ngengqondo Andikho zingqondweni Ukuthakatha
No of hospital admissions	Once for 2 years Psychotic episodes are managed at outpatient clinic	Once for 6 months Psychotic episodes are managed at outpatient clinic	None Epilepsy managed at outpatient clinic	Once for six months	Multiple psychotic episodes are managed at outpatient clinic
Level of education	Std 2 / Grade 4	Tertiary B Tech (teacher)	Std 4 / Grade 6	Std 7 / Grade 9	Std 5/ Grade 7
Locality (suburbs in greater Khayelitsha)	Browns Farm	Site B	Browns Farm	Browns Farm	Site B
Social security	2 x disability grant1 x childcare grant	1 x disability grant	2 x childcare grants	1 x disability grant	1 x childcare grant 1 x disability grant
Head of household	Culturally but not as breadwinner	No	No	Culturally but not as breadwinner	Yes
Household size	6	8	14	8	4
Primary source of income	DG, fruit vendor assistant & informal trading	DG, entering competitions	Social grants Cardboard collection	DG, seasonal fruit picking	DG, selling second hand clothes

37 See point 3.2.3 above

38 All registers that may identify individuals and households have been removed by using pseudonyms

Vuzi Bekwa was a 38 year old divorced male with a Grade 4 education. He shared a three roomed breeze brick[39] dwelling with his mother; a 28 year old profoundly intellectually impaired and physically disabled sister, a younger brother who was blind in one eye and being treated for tuberculosis, and a six year old child (a relative from the Eastern Cape) who was HIV positive. Vuzi's younger sister died during the study period from Aids related health complications. The dwelling was fenced, had electricity, an outside long drop toilet, a tap with running water in the yard and a small patch of land on which a vegetable garden was cultivated. Vuzi's mother, Thumeka, looked after children for relatives who paid her a portion of the childcare grant[40]. Caring for children supplemented the income she gained from a small spaza[41] shop that she ran, with Vuzi's assistance, from an informal structure attached to the front of their house. They sold decanted detergents and oil, sugar, sweets, cooked chicken feet and fried fish. Attached to the main house, Vuzi's room was made of corrugated iron and wood plastered with newsprint and cardboard. Built on sand with no floor covering, the room had a small window and contained a very old double bed. The room leaked badly during winter. He used the coil of a discarded hotplate, linked to a makeshift electrical connection, as a heater and spent a considerable part of the day when he was relapsed lying on his bed.

Vuzi was forced to leave school when he was in Grade 4 after his father died because his mother could not afford the school fees or the rent. The family was evicted from the house owned by the company that his father worked for. Thumeka reported that the family was extremely poor for many years following her husband's death. She managed to build the breeze brick dwelling which Vuzi has helped her extend with informal additions over the years. Vuzi had his first psychotic episode when he was 35 years old. He was hospitalised for two years and has had a number of brief psychotic episodes since being discharged; each episode reportedly precipitated by substance abuse or non-compliance with his medication. Prior to the onset of his illness, Vuzi worked as a newspaper vendor and was briefly married to a woman he reportedly divorced because she was an alcoholic. He became destructive (for example, smashed windows of cars parked in the street) and irrational (buying items that the household could not afford, for example a watch for R800) when he was ill. While his lack of judgement, lethargy (he slept a lot, especially after receiving his anti psychotic injection) and occasional aggression imposed a cost burden on the household, he played an important role in their survival by helping Thumeka run the spaza business and by securing casual employment

39 Breeze bricks are porous, hollow cement blocks approximately the size of a large shoe box.

40 At one stage during the study Thumeka was looking after three children under the age of five

41 An informal general dealership

as an assistant at a friend's fruit and vegetable vending business. He was very proud of the purple bedspread that he was able to buy with the money he earned as an assistant fruit vendor when he was well enough to work.

When we first met Vuzi he was waiting for his disability grant application to be processed. He had to reapply at regular intervals because his diagnosis (bipolar mood disorder) did not qualify him for a permanent grant. The instability of his grant caused considerable stress in this household who relied heavily on social security for their survival. They augmented the income from social security through the spaza shop and Vuzi's informal job as a vendor assistant. The household's financial situation improved markedly during the study period when Thumeka turned sixty and therefore qualified for a state pension. She also got married during the study period to a self employed elderly man who augmented his pension by making and selling lattice fencing made from a readily available local shrub. Thumeka invested her first few pension payouts in a washing machine as she was finding it increasingly difficult to handwash the constantly soiled clothes and bedding generated by Xoliswa, Vuzi's severely disabled and care dependent sister. She also bought a four plate stove and a deep freezer, both assets that enabled her to increase the range and volume of cooked produce that she was able to sell. Vuzi played a pivotal supportive role in this household by assisting his mother with labour (for example building maintenance; looking after the children and Xoliswa when Thumeka wasn't able to; digging the garden, running errands for and selling goods from the spaza business) and income (from his disability grant and a casual job he secured as an assistant to a fruit and vegetable vendor operating at the local bus station).

Siyanda Kamana was a 30 year old single male who lived with his widowed mother, two older brothers and their wives and his two nieces in Site B[42]. When we first met the household they were living in a two roomed breeze brick house without internal running water, electricity or toilet. Siyanda enjoyed entering competitions advertised in magazines, shopping malls (his family brought this information to him) and on the radio. Just prior to the start of the study he won a substantial amount of money (R30,000; approximately $300). This prize money enables the household to upgrade their dwelling to four rooms, a small bathroom and a kitchenette with running water and electricity. Siyanda's agency in entering competitions, his self reported primary occupation, continued to benefit this household throughout the study when he subsequently won prizes including a stove, hi-fi, bread maker and various smaller items such as watches and books.

42 A suburb in greater Khayelitsha.

Siyanda was diagnosed with schizophrenia during his final year at school. He successfully completed matric and a three year teaching diploma. He reported being unable to take up a teaching job because he was too socially reclusive, unable to concentrate and anxious. He assisted some learners, who came to the house, with their homework from time to time. Siyanda spent his time entering competitions and listening to gospel music. Towards the end of the study period he had started attending a psychosocial support group at the nearby day hospital and had secured a voluntary job as a survey assistant for a research project. The household travelled once a year to the Eastern Cape to consult an *igqira* (diviner). Siyanda believed that his mental illness was the result of "sperms (that) block your backbone which could lead to brain damage" and took various remedies every day to ward off evil spirits[43].

Sesetu Nombewu was a 25 year old woman who lived with thirteen other people (her parents, two younger and unemployed sisters aged 16 and 18 who both fell pregnant during the study period, three unemployed male relatives in their late twenties and five children ranging from five months to ten years) in a two roomed shack[44] that was situated on a plot littered with what appeared to be rubble and refuse[45]. The inside of the dwelling was cramped and unkempt. The household cooked on an open fire in their yard or on a paraffin stove when they could afford the fuel. An emaciated dog shared the dwelling that had an outside long drop toilet and tap with running water. During the rainy winter season I counted sixteen containers placed strategically to catch drips from the roof. There were two single beds in the larger room, a few broken chairs, a table with some cooking utensils and a mattress on the floor in the smaller room where the parents slept. The household reportedly survived on sporadic income from casual jobs, collecting and selling rubble and child support grants[46].

43 Further information from Siyanda's case study is available in a chapter that he co-authored anonymously during the research period with the researcher in a book on disability and social change in South Africa (K & Duncan, 2006).

44 A shack is an informal dwelling usually built on bare sand and made from corrugated iron, plastic sheeting, cardboard and wood offcuts

45 The apparent rubble was in fact a source of income for this household. They collected glass, cardboard, wood, iron, plastic etc. that they traded at the local refuse dump for cash. Sesetu's mother reported that they earned between R8 - R12 a day through this occupation; money that often made the difference between eating and starving.

46 Although Sesetu was eligible for a disability grant and could claim a child support grant for each of her children, she refused, much to the chagrin of her household members, to apply for these. She attributed her resistance to illiteracy (she said she could not fill in the requisite forms), her health condition (she believed that she was bewitched and did not therefore need a disability grant) and the poor interpersonal relationships amongst the household members (she said they wanted her to go to social services so that they could get her sterilised). They in turn accused her of being very aggressive and lacking insight. The researchers (re)connected Sesetu with the appropriate health and social services.

Sesetu's father died during the research period from unknown causes. He worked as a casual gardener and was, according to key informants and self reportedly, often drunk. Her mother suffered from chronic asthma. The children, some visibly covered with skin disorders, wore very little clothing in winter and summer. One five month old baby commenced treatment for tuberculosis during the research period. Sesetu's mother reported much tension in this household including rape (the eldest daughter's boyfriend was apprehended for raping Sesetu's youngest sister), frequent assaults (on one occasion during the study period Sesetu sustained a head wound from being hit with a brick that required stitches) and much arguing (reported by the neighbour who also complained that she often had to disconnect their electricity due to non payment of the connection fee)[47]. All the members of the Nombewu household had the last digit of either their left or right little finger cut off. They believed that the severed digit, plastered with a special mixture of soil, dung and herbs to the doorpost of a homestead in a rural Eastern Cape village, would provide a spiritual link with and protection from their ancestors.

According to her clinic card, Sesetu had a neuropsychiatric disorder that was exacerbated by grand mal epilepsy (not a mental illness). The epilepsy was not well controlled because she did not take her medication regularly, believing she did not need it as she was not ill but bewitched. Sesetu was often irritable, emotionally labile and was considered by her family members and neighbours to be affected by *umoya umdaka* (evil spirits). She married the casually employed[48] father of two of her three children during the research period and relocated to live with him in an informal dwelling that he built for them at the back of a shebeen[49]. Sesetu reported spending most of her time drinking traditional beer, talking to people, helping her mother pull the cart of rubble to and from the dump and sleeping, especially after a seizure. She lost a three month old baby during the research period when she fell asleep on top of the child one night, reportedly as a result of a seizure. Sesetu refused to use contraception and became pregnant again soon after losing this child. Her mother and sisters were very concerned about the way in which she treated her children; reportedly often beating and shouting at them. She did however take the youngest two children to preschool

47 Illegal electrical connections run between shacks in Khayelitsha. This neighbour, herself a disabled wheelchair user, was living a three roomed breeze brick house with an overhead electrical supply from which multiple extensions to neighbouring dwellings were made. This was a source of income for her.

48 Casually employed (on a first come, first hired basis) at a fertilizer company shovelling chemical mixtures into a grinder, Sesetu's partner was not given protective clothing. His hands and arms were itchy and blistered. Desperate to keep this seasonal job, he did not want to create problems by insisting on protective clothing. He believed that Sesetu was bewitched and was saving to take her to a traditional healer in the Eastern Cape. Sesetu reported that he regularly beat her. This was confirmed by her sisters.

49 A tavern

every day and her husband reported that he was satisfied by the way she ran their home.

Fuzile Sojola was a 50 year old male who sustained a head injury in a stabbing attack that left him with a left sided hemiplegia. He was unable to use his left arm and walked with difficulty using a walking stick. This physical disability was however not the main problem. A heavy drinker[50], he was also prone to psychotic episodes during which he had violent outbursts causing damage to property including setting property alight. He spent his days sitting on his own on a narrow wooden bench in a sparkly furnished, two roomed breeze brick house with electricity but no running water. The household shared an outside, long drop toilet with neighbours. The living room, with an uncovered cement floor, was bare except for a table with some cooking utensils and a wooden bench. The adjacent bedroom had a three quarter bed in it and a small bedside table and some boxes. An informal structure, attached to the back of the dwelling, served as the bedroom for the teenaged Sojolo daughters. I felt uncomfortable in this household on the odd occasion when the two unemployed, male children, both in their late twenties, were home[51]. This eight person household survived on Fuzile's disability grant and the money his wife, Noloko, made as a seasonal fruit picker on the farms near Stellenbosch[52]. Noloko stayed on the farm where she found work during the week and travelled home over weekends. This household underwent a dramatic change during the time that we knew them. Noloko, also a heavy drinker, converted to Christianity. Church members became involved with the household contributing assets such as chairs, a fridge, curtains for the window, a television and a new coat of paint to the interior and exterior of the house. Despite Fuzile's restricted occupational performance, his role in this household was highly valued. He was acknowledged as primary provider by virtue of his disability and the grant that he received every month. Both he and his wife reported that becoming involved in the church significantly increased the scope of his occupational engagement and the socioeconomic quality of their lives.

Dorcas Somngesi was a 55 year old woman who had been living with bipolar mood disorder for twenty eight years. She raised two children (one disabled with polio) on her own by supplementing her disability grant with a number of enterprises over the years, adapting her survival strategies to her fluctuating mental health. When we met Dorcas she was

50 Mainly umqombothi - traditional beer

51 My discomfort was linked to the possibility that they may act irrationally because they were heavily inebriated and smelling of marijuana every time we saw them. They were unable to give a reasonable account of themselves or their household when my research assistant and I tried to engage them in conversation.

52 A town in the Western Cape renowned for its wine and fruit agriculture

earning extra income selling second hand clothes and living in a very small, three roomed informal dwelling. The household of four had to make use of a communal tap and toilet within walking distance of their dwelling. She was raising her eighteen year old daughter's child. Her daughter was also mentally ill (we had to make a referral to the local clinic due to her irrational and aggressive behaviour). Dorcas's illness behaviour was also erratic. She would neglect to get her anti-psychotic injections because she disliked waiting in the long queues at the clinic. Signs of relapse included refusing to bathe, undressing in public and behaving bizarrely. Members of the public openly called her *uphambene* (mad), would throw bags containing faeces at her dwelling and try on clothes that she was selling, deliberately tear them and then run away, mocking her. She attributed her illness to *idliso* (a bad spell) and *mamlambo* (a spirit familiar from the green river snake) which she believed entered her as a young bride when she was forced to leave her natal village in the rural Eastern Cape to move into the *kraal* (rural homestead) belonging to her husband's clan. She was so unhappy that she went *umthandazeli*, (a trancelike state) in which she burnt down two huts thereby catapulting her husband's family into debt. She was tied up and kept locked up for two days before an ambulance arrived to take her to a mental hospital where she was treated for over a year. She subsequently divorced her husband and moved to Cape Town in search of health care and employment[53].

3.3.7 Data gathering methods: interview

Interviews[54] are inherently interactional events in which the talk is collaboratively produced (Rapley, 2004). They involve the co-construction of a story about life outside the interview and sometimes that life impinges on the interview as it unfolds[55]. Since talk is also situated in the wider cultural arena, interview data will speak to contemporary and local ways of experiencing, interpreting, and understanding the topic under discussion (in this instance, occupation)[56]. What happens between the interviewer and the interviewee may therefore be as much part of the data that is collected as the actual content of their conversation (Rubin

53 Dorcas's case study is presented in detail in Chapter 5. Selected as an exemplar of the basics of human occupation in the context of chronic poverty and psychiatric disability, many features of her occupational performance relate to the findings of the other four individual case studies which are available on request.

54 Interview may be defined as "a story that describes how two people, often as relative strangers, sit down and talk about a specific topic…They are social encounters where speakers collaborate in producing retrospective (and prospective) accounts or versions of their past (or future) actions, experiences, feelings and thoughts" (Rapley, 2004, p.16).

55 See 3.3.7.1 below: Vignette: an interview event unfolds.

56 It was not easy to convey what 'occupation' entails. We therefore avoided this word and focussed instead on probing in ways that elicited stories about time use including, roles, tasks, activities, meaning and purpose, outcomes, impact of impairments on doing the everyday things required for living etc.

& Rubin, 1995; Kvale, 1996). For these reasons I now elaborate on the technicalities and challenges of interviewing encountered during the study.

The quality of interaction that we were able to establish was significantly shaped by my research assistant, Akona Mbombo's, 'cultural insider' and professional status [57]. Akona and I drew intuitively on our professional reasoning and training as mental health practitioners to communicate openness, reassurance and the willingness to listen[58]. Establishing rapport was of critical importance for accessing relevant information. Remaining neutral towards informants was difficult due to the tacit socio-cultural expectations for dialogical exchange within the African worldview (Mkhize, 2004). In this worldview the personhood of individuals talking to each other is mutually implicated[59]. Akona established markedly different relationships in each household based on the exchange of culturally appropriate information, usually related to clan linkages with the Eastern Cape. My interactions with informants unfolded in a different way. Seedat, Duncan and Lazarus (2001), writing about the complexities of community psychology in post-apartheid South Africa, suggest that essential human processes are often omitted from accounts of our work as practitioners and researchers. The uncertainty and vagueness of 'not-knowing' at grassroots level (for example, being a cultural 'outsider') influences how interactions unfold[60]. They suggest that the discomfort of the dialectic (knowing yet not-knowing) is precisely what should inform and reform our work in the field. I share a vignette from an interview event as a case in point. Despite establishing congenial relationships with the participants, I often felt awkward during the interviews because I was unable to recognise the details of life impinging on the interview space. I made a number of significant mistakes because I did not, in the initial stages of the study, know how to observe and interpret non-verbal, cultural signals so readily

57 Akona Mbombo is a Xhosa speaking occupational therapist. He was born and raised in the Mount Frere area of the Eastern Cape and moved to Cape Town to do his professional training at the University of the Western Cape. Akona, closely connected to his clan structures, provided insights on the cusp between indigenous understandings of Xhosa people's roles, activities and tasks ie. their occupations and the Eurocentric descriptors of occupational performance in the occupational therapy literature.

58 Fontana and Frey (1994, p. 373-4) argue " as we treat the Other as human being, we can no longer remain objective, faceless interviewers, but become human beings and must disclose ourselves, learning about ourselves as we learn about the Other". Over time, we came to know details about each household that served as reference point for further research conversations and personal reflections about ourselves in relation to their needs.

59 This applied to the relationship that Akona established with informants. According to Mkhize (2004, p.47) "personhood in African thought is defined relationally". He points out that "because of the interdependence between the individuals and the community, personhood cannot be defined solely in terms of physical and psychological attributes... It is through participation in a community that a person finds meaning in life". Akona used a range of different greetings depending on who was talking to (socio-cultural precepts regulate how elder men, younger and older women and children are addressed); he selected which comments were appropriate about current local affairs (political affiliation is often tacitly understood and contested) and made considered references to affairs and clan matters 'back home' (rural regions of the Eastern Cape).

60 To deal with this, see research stance , point 3.3.1 above

understood by cultural insiders. The following vignette highlights some of the complexities of cross-cultural qualitative research which I found particularly challenging.

3.3.7.1 Vignette: An interview event unfolds

The Nombewu household lived in dire circumstances[61]*. Their material assets were precarious; reflected in the unkempt physical condition of their yard which was littered with refuse and discarded material with which they traded. When we arrived for an interview one day we immediately noticed that something was different. The yard was immaculately swept, the rubble neatly piled in one corner and there was an air of dignity about the façade of the dwelling. As we approached the open front door, we noticed that the inside of the dwelling too had been cleaned and rearranged. About ten people were quietly talking and seated around the perimeter of the room. I did not hear Akona telling me to stay outside because by that stage Sesetu (research participant), who ran outside to greet us, was gushing at me with a barrage of Xhosa words and unsolicited hugs (behaviour associated with her disorder). I noticed that the matriarch of the home was lying on a mattress on the floor in one corner of the dwelling. I entered, walked across the room, knelt down in concern and inquired about her well-being. She did not respond and appeared either asleep, ill or 'passed out' (drunk, as had been the case on previous visits). I still did not hear Akona. He had not entered the room, which was, I learnt later, the culturally correct thing to do. Sesetu told me that Akona was calling me and, greeting the people, I went outside. Akona was, quite rightly, most upset by my lack of sensitivity. He had immediately read the situation as a household in mourning (the father had died) and had responded in a culturally appropriate manner. What we should have done was stay outside. We should have presented the elders, who had travelled at great cost from the Eastern Cape, with a monetary gift. If invited in, we should have sat in the circle with everyone else and definitely not spoken to the widow, who it transpired, was following custom by going into a mourning trance for a period specified by the ancestors and monitored by the elders.*

This vignette highlights how cultural life outside the interview entered directly into the quality of dialogue established during each interview. Akona first cleared the communal space (cultural turf) between himself and the respondent before (re)affirming the 'ins and outs' of the research process (for example use of tape recorder, informed consent, duration, purpose) for that particular research event. Informed consent, in particular, became an ongoing ethical commitment (re)negotiated throughout the study. The culturally sensitive approach described here aligns with Johnson's (2002, p. 288) notion of "strict reciprocity"

61 See Chapter 3, page 75

in which Akona (and myself when asked) exchanged information with participants[62]. Critical to the discussion here was the impact that reciprocity had on the interview process and the participants. Not only is reciprocity a fundamental value in African worldviews (Higgs & Smith, 2006; Mkhize, 2004), but the professional, ethical imperative of prolonged engagement required us to become involved in the health and welfare needs of participants when indicated, even though, according to Kvale (1996), a research interview should not become quasi-therapeutic. Reflexivity proved useful in maintaining neutrality towards the data, if not towards the emerging health needs of participants (discussed later).

3.3.7.2 Interviewing and ethics

In-depth interviewing may breach ethical boundaries especially when there are language barriers at play (Swartz & Drennan, 2002). The interviewees' exploration of personal experiences of occupation and motives for doing certain activities and tasks occurred within the context of the evolving research relationship and could not be predicted[63]. According to Duncombe & Jessop, (2002) there is always the possibility that the interview might lead the respondent into new insights which s/he may have preferred to leave unexplored. The rapport achieved with household members however led to unanticipated disclosures demonstrating agency on the part of interviewees who used the research interview space as a source of support and potential intervention. Some interviewees wanted to use the interview space to address household dynamics claiming that their voices were silenced either because they were the youngest; disabled or female[64]. The point here is that a fine ethical line existed between interviewing for data gathering about occupation, disability and poverty; using the content of the interview to discern a health condition which was exacerbating the burden of poverty and becoming quasi-therapeutic[65].

62 This meant exchanging some form of assistance or information for example; we helped Siyanda to sort out his student loan debt and transported Sesetu to a specialist clinic to obtain her medication. We had to consider the ways in which these actions influenced the quality of relationships that developed and the potential contamination of data that was gathered in subsequent interviews.

63 For example, during an interview some months later with the widow described in the vignette (point 3.3.7.1), she talked about the extreme financial hardship that her husband's unexpected death had precipitated and that the burden of daily survival, now her responsibility, was proving too much to handle physically and emotionally. Drawing on our mental health experience, Akona and I assessed her to be clinically depressed and were able to link her with a clinic where she was prescribed anti-depressants. She responded well to this intervention.

64 Rapley (2004, p. 25) suggests that "interviewing can be used as a way to enable previously hidden, or silenced, voices to speak". The interpersonal conflict in one household including sexual and physical abuse surfaced during interviews highlighting the impact of social dysfunction on household occupational patterns.

65 As researcher-therapists we were ethically obliged to make referrals when we discerned particular health and social needs in participants.

3.3.7.3 Interview and observation process

In keeping with interview convention, Akona and I made use of an interview outline for each stage of the data gathering process[66]. The content of the guideline was initially generated using occupational science (Christiansen & Townsend, 2004) literature alongside our interpretive thoughts about areas to cover in view of the research questions. The questions changed over the life-cycle of the study according to our emerging understanding of the data and, during each interview, according to the responses of participants. Of particular interest was an in-depth interview on and participant observation of the occupational performance demands and subsequent activity analysis (Hersch, Lamport & Coffey, 2005) of one income generating occupation performed by the disabled person/ key informant in each household[67].

The process of a good qualitative interview is dependant, in part, on informants being capable of 'reflexive subjectivity[68]. This was not possible because the purpose of the study required a particular type of informant[69]. I found the interviewing process limiting because I had restricted control over which topics were pursued and had to rely on Akona's professional skill in client centred practice to draw out thick descriptions of significant issues pertinent to the study objectives. We chose not to do simultaneous interviewing and translation because we found it disrupted the narrative flow of interviewees who were already struggling with the negative (and on occasion positive) symptoms of their psychiatric disorder. Although Akona's clinical interviewing skills proved to be a sound foundation on which to build, we spent considerable time fine-tuning the interview methods to ensure substantive qualitative data was elicited.

66 See Appendix 6

67 Participant observation is an ethnographic method which "increases the involvement of the researcher in the phenomena" (Parker, 2005, p.37). We observed (and asked questions to clarify meanings as the need arose) the execution of tasks and activities associated with selling second hand clothes (Dorcas), collecting recycled rubble (Sesetu), being a vendor assistant at a fruit and vegetable stall (Vuzi), entering competitions (Siyanda) and just sitting in a bare room with nothing to do (Fuzile). I also slept over in a shack on occasion obtaining observational data about occupations and occupational performance in the confines of the dwelling and in the neighbourhood. See Appendix 6 for photographs for examples of observation spaces.

68 Reflexive subjectivity refers to having a strong sense of identity, biography and history, being able to share personal perspectives, opinions and experiences with insight and being able to tell chronologically linear stories as well as comment insightfully (Alldred and Gillies, 2002).

69 Participants exhibited psychiatric symptomatology for example thought disorder (tangentiality, blocking, paucity of ideation, paranoia), limited insight, blunted and fatuous affect, poor concentration, agitation and/or low motivation. It was important to verify interview data with co-lateral information from other informants in the household. Each of the participants had one or two periods of mild to moderate relapse during the study. These were resolved by going to the psychiatric clinic for an adjustment of their medication. None were readmitted to hospital. The narrative was therefore sparce.

3.3.8 Data management: translation and transcription

The role of the translator/transcriber is central to the process of understanding what the respondents actually said as well as how their intersubjective experiences are conveyed from the spoken word to the translated and transcribed text[70]. I was excluded from both these processes due to my isiXhosa illiteracy. Zavos (2005) argues that translation as equation is impossible because different languages inhabit different worlds. He points out that the inequalities of power and language hierarchies (for example the hegemony of the English language) are often enacted in translation, making it a potentially violent enactment of cultural and linguistic incommensurabilities[71]. Incorrect translations of words with multiple meanings, over-simplification of complex phrases and cultural idioms, misrepresentation of emotional tone, pace and volume, and inaccurate punctuation were inevitable raising concern about the quality of the data. This meant that I had to pay particular attention to training and checking the translations and transcriptions done by my two data managers. I therefore compiled an orthography of isiXhosa words that cropped up regularly during interviews and that posed particular linguistic challenges during the translation and transcription process[72]. There are no words in isiXhosa for 'poverty', 'disability', 'occupation' or 'rehabilitation'. The word 'poverty' may, for example, be translated as *intlupheko*, but, depending on the context of the narrative and where it is placed in a sentence, it may mean any one of the following: trouble, affliction, worry, grief, annoyance, want, inconvenience or frustration.

The task of translation and transcription was complex. As a quality control measure, I had to address the ethical imperative of confidentiality and the importance of capturing the respondents' narratives verbatim with due recognition of cultural nuances and linguistic accuracy. The potential existed for the translator/transcribers to project their own

70 According to Alldred and Gillies (2002), data management is one of the least problematised parts of the research process, yet is fraught with complex ambiguities of language, communication and interpretation. They argue that "transcripts are artefacts and we should acknowledge that we researchers produce, rather than retrieve them shell-like from the sea. We are active in producing the particular account and that the transcript therefore bears traces not only of ourselves as interviewer, as the culturally situated and particular individuals we are, but also as interpreters" (Alldred & Gillies, 2002, p. 161).

71 To manage these tensions so that 'lesser-ranked' voices are fairly represented in the dialogic space, Zavos (2005, p. 12-127) suggests that translators become mediators and ethical agents who, in the act of translation, view " language as history (every word is inscribed with discourses and social practices), culture (words betray or highlight values, class, gender etcetera), experience (words reveal subjectivities of the 'I') and embodiment (words enact what they name)". I did not have the benefit of professional translators who could apply this kind of rigour and relied on two social science undergraduates with some experience in translating and transcribing Xhosa qualitative research data into English and back-translating.

72 Appendix 2.

interpretations onto the data as they struggled with the messiness of the recordings[73]. They had to listen to some disturbing stories, make sense of strange responses (some participants had thought disorder) and deal with their own emotional reactions to these occurrences[74]. These are complex methodological challenges. I therefore chose not to make use of a computer based coding package because I believed that this tool would restrict my ability to engage the tacit, culturally imbued meanings of textual codes with due recognition of the mental state of the informants. I spent time debriefing the data managers after each batch of tapes were translated, checking procedural issues and clarifying terminology by going through the transcripts. The orthography of isiXhosa words (Appendix 2) was confirmed through discussions with isiXhosa speaking colleagues about their situated meanings. Grammar had to be edited where exact translations were too complex. I also had parts of the tapes back translated by an independent translator to verify the accuracy of the transcripts.

3.3.9 Data analysis and audit trail

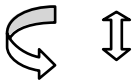
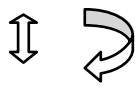
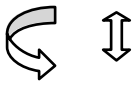
Transcription, if done by the interviewer him/herself, adds another layer to analysis by repetitive listening of the tapes. Since this was not possible for me, I read the translated transcripts many times identifying structures within the text and interpreting these in terms of Kvale's (1996) four approaches for the analysis of meaning summarised in Table 8.

73 Fabian (2001, p. 28), writing on the perils of translation and transcription in ethnography, points out that "on the dark side of understanding there is not-understanding and misunderstanding". The translators and transcribers used for this study were not trained in mental illness and it is possible that they misunderstood some parts of the recorded data.

74 For example, one transcriber confessed to laughing at the "crazy" responses of one unwell participant. The essence of the respondent's words had to be clarified.

Table 8: Data analysis: procedures for meaning interpretation

(summarised from Kvale, 1996, p. 191).

PROCEDURES	MEANING ANALYSIS
Condensation 	Multiple processes: a) identifying 'meaning units' as codes; b) compressing essence of textual data and field observations into meaning units; c) rephrasing text into succinct, descriptive in/deductive thematic codes (statements) and d) clarifying core emerging ideas from reading transcripts in their entirety.
Categorisation 	Creating categories and subcategories (grouping & clustering) of codes with similar or paradoxical thematic meaning; noting patterns, seeing plausibility. The conceptual framework of the basics of occupation was used to identify the sub categories for deductive thematic analysis (see point 3.3.3 above).
Narrative structuring 	Temporal and social organisation of text into stories with coherent patterns or plots; building a logical chain of meaningful events or critical speculations.
Meaning interpretation	Speculative understanding of ideas within broader frames of reference; interpreting meaning behind or beneath what was directly expressed; creating conceptual / theoretical coherence; identifying points of learning, making assertions

Data analysis entailed an iterative process as the arrows in Table 8 indicate (See appendix 7 for audit trail). Meaning interpretation evolved over a long period of time including reflexivity (Parker, 2005)[75], discussion with colleagues (co-data analysts) and member checking. I engaged three expert mental health practitioners as co-data analysts to assist with interpretation of different sections of the data: two psychiatric occupational therapists (one was also a trained *sangoma* [76]) and one nurse/anthropologist. I used these particular individuals as co-data analysts because they had an intimate knowledge of township life, having either lived, studied or worked there themselves. As expert social science practitioners, they were able to interpret the data in light of their knowledge about African belief systems, poverty, occupation and psychiatric disability[77].

3.3.10 Data interpretation and verification

A multi-lensed and multilayered approach to analysis, interpretation and verification is in keeping with case study methodology where the purpose is not to generalise but to explicate the case so that understanding may occur[78]. The first layer of analysis involved open coding in consultation with the co-data analysts. Rigour was ensured by being explicit about which

75 See point 3.3.1 above

76 Traditional healer

77 Henning et.al (2004, p. 8) suggest that the research instrument, the data analyst, "needs to have the ability to zoom in on detail ... exchanging the telescope for the microscope of social science". Conversations with these three individuals enriched my understanding of subtle cultural details within the data.

78 The understandings emerging from the case studies about human occupation would however have generalised applicability for psychiatric occupational therapy practice in the context of poverty

research questions were being applied to the text; the observation under discussion or the construct under review so that co-determination of meaning by the data analysts within each code could occur. Each co-data analyst, having received a hard copy of selected sections of the transcribed and translated data, the research questions and the data analysis procedures, was asked to use their particular theoretical perspective and practical knowledge of the field as a critical lens. Interpretation started by first seeking consensus about what we thought the interviewee understood the meanings of his/her statements to be, or what the observed behaviour may have meant followed by an exploration of shared understandings of the topic within different contexts (for example personal, geographical and socio-cultural and political). I did the second layer of analysis of each case study on my own. This involved deductive, axial coding using the basics of occupation (Nelson and Jepson-Thomas, 2003, p.111) as organising frame for analysis[79]. Interpretation was informed by drawing on theories of occupation (Christiansen and Baum, 2005; Christiansen and Townsend, 2004a; Kramer, Hinojosa and Royeen, 2003; Wilcock, 1998b, 2002).

It was not logistically feasible, as verification requires, to present every interpretation to the interviewee for confirmation or disconfirmation. I did however return to some of the households with some of the findings and made adjustments where indicated. I involved Siyanda as co-analyst of the transcripts of sections of his personal interviews by giving him a hard copy with the request that he make written notes of further thoughts, meanings and interpretations thereby arriving at a revisionist understanding of his interview data. This led to a joint publication between me as an academic and Siyanda as a research participant putting into practice, in some small measure, the deconstruction of power in the research relationship discussed earlier and the paucity of literature on poverty and psychiatric disability (K and Duncan, 2006)[80].

3.3.11 Rigour and limitations

The rigour of an investigation should assure readers of the authenticity and trustworthiness of the information[81]. Trustworthiness was promoted by subjecting the research process to regular checks for plausibility (discussions with co-data analysts), weighing evidence of how

79 See Chapter 2, point 2.2.2, pages 20-21.

80 See point 3.3.1 above and Chapter 1, footnote 34.

81 Lincoln & Guba (1985) suggest that trustworthiness is promoted by attending to the credibility (truth value: rigorous implementation of methodology and methods), transferability (applicability: accounts of the findings are plausible because the reader can recognise familiar features from other contexts), dependability (consistency: internal coherence of reported findings) and confirmability (neutrality: verifiable audit trail) of the findings.

events were reported (noting patterned regularities across research events and observations by debriefing and reflective discussions after every fieldtrip with research assistants), following up on surprises (returning to informants with questions), triangulating with theory (literature review), and obtaining feedback from informants (focus group to clarify findings and experiences). An important component of rigour was to foreground bias and limitations (Krefting, 1991). I indicated earlier how my Afrikaner cultural roots, white female identity and locality as an academic-researcher-therapist shaped my subjectivities[82]. Despite being well intentioned to be 'objective researchers' intent on recognising and dealing with the power relationships between ourselves and the participants, some accounts in households were heard with greater commitment and connection than others (Martin, 1996). On occasion, either Akona or myself did not have the emotional energy to engage with a particular household because we found their circumstances too harrowing to face (our defence was to rationalise " let's visit them next time" or "I am too tired to deal with their problems now"). Psychodynamically, these responses may suggest that we introjected some of the participants' projections of deprivation or that we were defending against acknowledging our own deprivations (Parker, 2004; Watermeyer, 2006). The point here is that we paid attention to rigour in the dynamics of the data gathering process (methods) [83] as well as in working as objectively as possible with the findings.

3.3.12 Research ethics

This study was granted ethics approval by the Department of Psychology, University of Stellenbosch in April 2004[84]. Parker (2005) cautions that social inquirers can be blithely unaware, simply uncaring or reflectively deliberate when thinking through the ways in which their everyday treatment of others (research participants) is intimately linked to wider social forces. During the course of the study, ethics turned out to be fraught with ambiguity, conflicting interest, fine lines, judgment calls and awkward decisions[85]. I came to understand

82 See point 3.3.1 above. Grosz (quoted in Doucet & Mathner, 2002, p. 138) warns that despite attempts to be highly reflexive, the "author's intentions, emotions, psyche, and interiority are not always accessible to readers, [and] are likely to be inaccessible to the author herself". I kept a record of debriefing sessions as well as a journal documenting critical moments of learning.

83 Rigour in the research process involved grounding practice within relevant qualitative research literature and methods attending courses in qualitative research methods and consulting qualitative research experts (personal communication with Dr. M. Savin Baden; Dr. M Kaag and Prof. R. Watson).

84 Ethics cannot be relegated solely to the so-called 'ethics approval' by an ethics review board because, as Miller and Bell (2002, p. 54) argue, "this can obscure the need to continually reflect on the ethical implications of researching peoples lives".

85 Difficult questions arose for example: would consent to participate be predicated by the participant's anticipation of some perceived benefit? Would the power dynamics between Akona, myself and the informant override voluntary agreement to participate?

that morality in research cannot be separated from the politics of power which may or may not be imposed through the rigid application of ethical codes and principles[86]. Informed consent, confidentiality, beneficence and anonymity became a series of moral choices that had to be made in situ during every encounter based on Akona's and my commitment to the simple edicts of research ethics proposed by Silverman (2003): do no harm, do not cheat, respect difference and withhold judgment. The process of informed consent[87] in this study is used to illustrate some of these dilemmas.

3.3.12.1 Informed consent: Dorcas

To speak of autonomy, protection and benefit in the Xhosa culture is to speak, amongst others, of submission to patriarchal authority, interdependence and participatory decision making (Tjale & De Villiers, 2004; Shutte,1994). Although Dorcas had been living independently for many years and was the sole breadwinner of a household of four, she was not culturally expected to act as an autonomous agent (Deshmukh-Ranadive, 2005) nor was she someone with diminished capacity (warranting proxy authorisation), despite her enduring mental health problems. She was simply who she was: a mother, a sister, a grandmother, an aunt, a second hand clothes dealer. Culturally her protection (and, it could be argued her vulnerability) lay in her submission to her elder brothers who were, as it transpired during the research process, the appropriate persons to grant informed consent on her behalf. As a woman without a husband, they were 'responsible' for 'looking after her'. We were informed by cultural insiders that the brothers would deliberate (through decision making processes within the extended household structure) about the advantages and disadvantages of her involvement in the research project and base their decision on whether she should participate or not on cultural norms such as interdependence and resource sharing (Deshmukh-Ranadive, 2005). If they understood that Dorcas would gain materially in the form of food parcels her creditworthiness and bargaining power within the extended household infrastructure may have been enhanced but, paradoxically, her vulnerability may have been increased. Firstly,

86 Research ethics according to Parker (2005) means attending to the political issues that straddle the gap between anticipation and reflection. He suggests that the moral imperatives for ethics is firstly transparency about what transpires between the means and ends of the research process; secondly representation of 'Others' using language that has been carefully considered for its political consequences and thirdly using reflexivity as a way of managing the subjectivity of the researcher and the dialectical (contradictory and mutually implicative) relationship between the researcher and the researched.

87 See Appendix 8a,b for informed consent forms in Isixhosa and English. Informed consent has been defined as "the knowing consent of an individual, or a legally authorized representative, able to exercise free power of choice without undue inducement or any element of force, deceit, duress, or other form of constraint or coercion" (Protection of Human Subjects, quoted in Fluehr-Lobban, 2003, p. 166). This definition rests on an understanding of the individual as an autonomous subject who can make rational decisions about their own interests; it leaves little room to consider how social contexts affect such decisions (Miller & Bell, 2002; Alldred & Gillies, 2002).

she would be expected to share whatever scarce staple foods she received, thereby repaying debts she had already incurred with the extended household or alternatively, by sharing the goods, she would be building a buffer of goodwill credit against future hard times. Secondly, by receiving attention and food from us in lieu of time that she could have spent generating an income, she opened herself up to jealousy and possible suspicions that she was also receiving money and 'hiding' it from the household, which in turn would potentially impact negatively on her social capital[88].

In this example, I was torn between the ethical imperative of gaining informed consent from Dorcas herself on the one hand (because I stood in solidarity with her spirit of independence and against her social marginalisation as a disabled person and as a woman) and on the other hand, the moral act of minimising her vulnerability (vulnerability arising firstly, from subtle coercion on my part because I needed her story for my research and secondly, from potentially negative socio-economic repercussions because I failed to follow due cultural processes in seeking consent from her brothers). There are no clear cut answers to these kinds of ethical dilemmas but they were managed, as Parker (2005, p. 25) suggests, by "fidelity to the commitments made during a research event, staying true to what happened and reflexively attending to the institutional location of historical and personal aspects of the research relationship". The middle path involved spending time helping participants to understand the study problem and being honest about our own struggles to do the right thing. These were usually met with understanding and advice on culturally appropriate ways of managing ethical dilemmas.

3.3.12.2 Anonymity and confidentiality

Another point of ethical concern related to anonymity and confidentiality. Before entering the Kayelitsha and Browns Farm community, the research team had to seek permission from recognised community 'gatekeepers' to proceed[89]. Gatekeepers consented to co-operate once they were satisfied that they had been adequately informed about the research process, particularly with regard to participants and ways in which households and the broader community stood to gain from the encounter. Anonymity under these circumstances remained an ideal because, in a communal environment, there is often an expectation that something will change when researchers enter the community, that people will come to

88 For these and other complex social reasons, we distributed food parcels (see footnote 20) in inconspicuous bags to prevent neighbours seeing exactly what participants were receiving from us.

89 Elected street representatives and managers of the two DPO's with whom we worked. See point 3.2.4 above.

know what has changed, for whom and how, and that gatekeepers will be kept informed about developments so that they can continue monitoring the welfare of people involved. In keeping with these expectations, we kept consumer organisations informed of progress and, where possible, involved participants themselves in sharing information thereby obviating the need for confidentiality. Thinking about likely outcomes and specific benefits helped in making a final decision about ways to respect participants' rights and dignity (Snyder, 2002). Termination is closely tied to the spirit of informed consent. Having established the terms of engagement at the beginning of the study and checking and affirming them throughout the project's lifespan, we were morally obliged to signal in advance when termination would occur, thereby giving both parties time to reflect on any issues that needed to be resolved. We held a termination focus group with index participants at the end of the study (see Appendix 6 for questions). They had not met each other before the event and were able to share their perspectives on the research process having had different experiences and understandings of the purpose of the study. Creating a space for feedback and clarification of what would happen to the findings re-affirmed their original informed consent positions[90].

3.4 GLIMPSES OF A RESEARCH EVENT

Based on extracts from my study journal, the following vignette describes a typical research event with the aim of orientating the reader to the research locality. Substantial use was made of reflexivity throughout the research process[91]. Eight instances are highlighted via footnotes, triangulated with literature and examples of reflexive questions raised by research events. It is written in the present tense to create a sense of presence for the reader.

Akona and I arrange to meet at a mutually convenient time on a Saturday afternoon outside his apartment in Observatory, a suburb in Cape Town. Last week Akona called to postpone our fieldtrip because his contacts in Khayelitsha said the situation in the township was too volatile due to a spate of violent incidents between members of rival taxi associations and public bus companies. I am grateful for his advice and look forward to hearing his perspectives on the politics behind the latest spate of civic unrest. Things have settled down and today we will go to the township in my old Citigolf (Akona avoids using his new Citigolf because it is a favoured car for hijackings). I have checked the tyres and petrol (for safety reasons we do not want to get "stranded" along the 130 kilometer round trip) and, as a precaution, I have taken anything that

90 As a symbolic gesture of termination and in a spirit of appreciation we took the group for a tour of my offices, the university campus and a picnic to a scenic spot on Table Mountain that none of them had ever visited despite having lived in Cape Town for many years.

91 See point 3.3.1 above.

might attract a 'smash and grab' attempt out of sight inside the car (it is a weekend afternoon and the shebeens (informal taverns) will have had a busy trade all of Friday night (pay day) which increases the likelihood of drunken, random behaviour)[92]*. I dress modestly and take no money, only a cellphone, diary, note books, tape recorders and depending on the purpose of the visit, we take food parcels to the value of R30 (+/- $3) per household as tokens of appreciation for their time and effort in talking to us.*

When Akona arrives we sit for a while in the car going through the objectives of the visit (for example we review the interview outlines based on our emerging understanding of the issues we want to explore). We get the two battery powered tape recorders ready (there is no electricity in the dwellings and even if there was we would not want to make use of it given the high cost of energy to poor households)[93]*. Today we aim to set up appointments for the next round of interviews. Households do not have telephones so we make arrangements through informal visits which also enable us to build relationships and gather observational data. Sometimes we arrived to find no-one at home, necessitating another trip because face to face arrangements are culturally more appropriate than leaving written notes (some participants are semi-literate) or messages with neighbors (some households do not have good relationships with their neighbors).*

Driving towards Khayelitsha we pass an open stretch of 'veld' (undeveloped common land) on which a few cattle and goats roam. There are also about five informal, domed structures erected from wooden poles, refuse bags and grass. The structures house young Xhosa men who have, for between four and five weeks, isolated themselves from their community to attend to the circumcision initiation rites of passage into manhood. Akona expresses his distress at the apparent erosion of cultural norms and values which, he explains, probably accounts for

92 The tone of the vignette up to this point is one of vigilant suspicion… as if violence is an inescapable feature of local communities. Buchanan and Higson-Smith (2004) confirm this perception with statistical evidence pointing out that the high incidence of crime and violence in South Africa may be attributed to socio-economic inequalities, poverty and deprivation. In which ways are the occupations of research participants influenced by these volatile and unsafe social circumstances?

93 Access to electricity and water are critical for small business enterprises such as selling ice lollies, chicken pieces or tripe from a dwelling. These are viable income generating occupations for housebound disabled people. Ballard, Habib and Valodia (2006) provide a sobering report on the high incidence of electricity and water cut offs by local governments in poor communities because of non-payment of rates. Desai (2002) argues that it is not a 'culture of non-payment' that is at play but an 'economics of non-payment' whereby individuals simply cannot afford services as a result of their marginalisation from employment in the formal sector. How do local government decisions such as these impact on the occupational choices and income generating opportunities of participating households?

some of the problems amongst youth in the township[94]*. According to him the performance of circumcision rites amid a bustling township suggests disintegration of social values. He also complains about financial exploitation by unscrupulous elders who no longer adhere to the principles of initiation in which young Xhosa men should 'go to the mountains' in the Eastern Cape (to be close to their tribal roots). Akona tells me about his village in the Eastern Cape and the role of apartheid politics in the exacerbation of poverty in the former 'homelands'. As a member of the Pan African Congress (an opposition party to the African National Congress), Akona shares his neo-Marxist views on the liberation struggle in South Africa. I learn much from him as a cultural insider.*

We enter Khayelitsha and I navigate the car past overloaded taxis driving recklessly across the road, their hooters impatiently sounding to attract prospective travellers. Kwaito (local hip-hop) music blares full volume from their open windows. I concentrate on the road to avoid people, potholes, litter (have had a number of nails in the car's tyres) and electrical cables strung across the road between dwellings. I drive slowly around chickens and goats pecking at refuse and children playing with old tyres and cardboard boxes; past informal traders selling their wares from spaza shops (general dealers) or open fires (the smell of barbecued meat and smoke hangs like a blanket in the air); women washing clothes at communal taps; youth 'ama kheka-kheka' ('just looking' at life going by); smartly dressed women in red, white and black uniforms[95] *carrying Bibles on their way to a Methodist church meeting; a crowded shebeen and inebriated men clutching their bottles of liquor as they stagger off pavements. Here and there we see someone in a wheelchair or walking with crutches trying to navigate an inaccessible curb. I stop while a young child runs to pick up a toddler that has crawled into the road, it's mother nowhere in sight. I remember the African saying "it takes a village to raise a child"*[96]*. Children wave with smiling faces and shout 'mulungu!' (white person). I am a novelty and clearly an outsider.*

94 Makgoba (1998) in his edited exposé of the African Renaissance suggests that paradoxes of Westernisation and tribal enculturation need to be actively managed for development to occur. How are occupations influenced by this paradox?

95 These uniforms signal that they are '*bomanyano*', women of unity who are the bedrock of the community. The *bomanyano* were very active in the townships during the apartheid struggle sending out the message "you strike a woman, you strike a rock". How does this unity affect the occupational choices that women are able to make?

96 Tacit to these observations are three dimensions of township life of importance to this study: the informal economy; kinship structures and income generating contracted occupations. Devey, Skinner and Valodia (2006) provide a cogent argument for a 'work' characteristics-based definition of informal work because without this it remains impossible to determine the number of workers in the informal economy. Unemployment figures are therefore likely to be skewed. The greatest asset of the poor is their capacity for labour and their ability to draw on kinship structures to support income-generating occupations. What contribution, if any, do disabled people make to the informal economy and what are the implications of this for socio-economic policy? (Seirlis and Swartz, 2006).

We park in front of a spaza shop where a group of men are playing pool. We have chosen this place deliberately because the shop owner knows us and will keep an eye on the car. We make our way through a dusty, littered alley, winding between shacks towards Dorcas's dwelling. Her emaciated dog greets us as we approach the closed door - she is not home. A neighbour tells us she is probably trading at one of her usual sidewalk spots. Back to the car, another drive around until we find Dorcas sitting with her back against a fence, legs stretched out in front of her, her face painted white with sun screen and surrounded by second hand clothes spread out on a very dusty blanket for customers to view. She is nodding off in the blazing heat and smiles sleepily when she recognises the car which I park so that we do not obscure her business from passers-by.

This time she looks well. There have been times when her mental state has been either visibly depressed or hypomanic. We notice that Modloko, her friend and 'trading partner', is not present and we wonder why (on a previous occasion Dorcas had alluded that she felt Modloko was exploiting her and that the police were investigating her for drug trafficking). I hear passers-by commenting that the 'social workers' have arrived ... we are already known in the neighbourhood. After we have exchanged greetings (Akona translates and interprets for me) and have enquired about her health, family and recent trade (she reports that she made R75 (+/- $8) from the last bag of clothes that we brought her), Akona negotiates a suitable time with Dorcas for the next interview. He reiterates the purpose of the research and confirms her rights to refuse should she so wish[97]*. We hope she will remember (this depends on her mental state- poor memory). We take our leave and move on to the next household. It takes three to four hours before we have secured appointment times with all five households.*

On one occasion when we arrived to conduct an interview with Dorcas the following transpired: I help Dorcas pack up the clothes. Akona assists her by carrying the refuse bags she uses to transport her stock to the Rastafarian shopkeeper whom she trusts to store her. Dorcas, who is overweight and sweating profusely, refuses my offer to drive her home, choosing to walk instead. On arrival at her dwelling fifteen minutes later she is out of breath and I offer to get her a glass of water. I fetch a cup from the "kitchen" section of the dwelling and notice that there is a some 'phutu' (maizemeal porrige) in a pot on a small table, a kettle on the primus stove (paraffin) and a pocket of onions. There appears to be very little other food. The fridge is

97 Erving Goffman's (1962) seminal work on stigma and social identity is relevant here. He argues that both disability and unemployment are stigmatised and influence the identities and defence mechanisms that people assume in dealing with prejudice. How was Dorcas's identity shaped by her mental illness and her status as a second hand clothes seller?

now used as a cupboard because she has not been able to afford electricity for a few months as she has been paying off a debt. I have to fetch the water from the communal tap some distance away because the water container in her kitchen is empty. In the mean time Akona sets up the tape recording equipment in the 'lounge' area of the dwelling. Dorcas sits on a very worn two-seater couch; Akona and I sit on crates. The walls are covered with old newspapers and the few linoleum off-cuts on the ground (there is no flooring) barely stop the dust from rising as we settle down for the interview. The front door has to stay open because there is no window or electricity for lighting. The room is very stuffy, hot and dark. In winter it is freezing cold and we sit surrounded by buckets to catch the water dripping from the ceiling[98].

Akona begins preliminary informal conversations aimed at brokering access according to cultural norms, checking her mental state and acquiring verbal informed consent. He conducts the interview in Xhosa with sporadic translations when appropriate and has positioned himself for optimal engagement in the ensuing dialogue which takes, on average, between 1-1½ hours. I sit to one side on a crate so as not to infringe too much on the interview process while monitoring the recording equipment and swotting flies off my face and legs. I follow the interview through observation, taking my cues from Akona and watching Dorcas. When indicated, I clarify or ask Akona to probe deeper[99].

About twenty minutes into the interview, we hear a baby cry from behind the curtain that separates the 'lounge' from the bedroom; a small room approximately the size of two double beds. Dorcas had not yet told us that her twenty year old unmarried daughter, Noluthando, had recently given birth to a second child. Dorcas says she is worried about her daughter because she is behaving strangely and irresponsibly. She tells us that they have named the baby boy 'Akona' because of our involvement with the household. Dorcas calls out and from behind the curtain appears a girl-child relative (nine years old) carrying the baby. She has been taken out of school and brought to Cape Town from the rural Eastern Cape to look after the baby while Deborah trades. Dorcas wants to take the baby but I offer to let it lie down on my lap so that

98 Coulsen, Napier and Matsebe (2006) discuss universal access to housing in South Africa making the point that uptake of special housing subsidies by poor disabled people has been slow. Eligibility criteria pertain only to physical impairments. Why are psychiatrically disabled people discriminated against in this way by housing legislation?

99 Does the tape recorder influence the talk and if so how and why? What does my presence, sporadic probing and non-verbal behaviour imply? The tape recorder is one of a number of variables (besides physical space, status, gender, ethnicity, season) that create a particular social context for the interview communication (Warren 2002). It raises issues of trust and motive, especially for individuals whose mental illness predisposes them to paranoia and therefore needs to be managed by making it a topic for discussion before, during and after each interview. What repercussions may there be for Dorcas's mental health as a result of the interview?

the interview can continue. My training as an occupational therapist alerts me to the baby's abnormal reflexes: it presents with mild features of cerebral palsy and I become aware that we cannot continue with the interview because Dorcas is too distracted. Baby Akona is still crying and I ask the girl-child to fetch me its bottle. She brings me one filled with hot water from the kettle. I ask Akona to ask her if she normally feeds the baby with hot water from the kettle: she says yes and takes the baby to the bedroom to change its diaper. With Dorcas's permission I enter the bedroom in which stands a three-quarter bed and some boxes. It is dark, has no ventilation and it takes some time before my eyes adjust. The girl-child changes the diaper while Dorcas watches and Akona informs me that this is the cultural way of role modelling mothering skills. I briefly tell him about my observations and, without raising Dorcas's concern, Akona encourages her to take the baby to the clinic as soon as possible. I make a note in my diary to follow this referral up with the relevant clinic.

As we are leaving Noluthando, the baby's mother, arrives. Dorcas has told us that her daughter often physically abuses her and it is clear why. Her face is expressionless; her eyes unfocussed; her movements aggressive: she appears inebriated, drugged or psychotic. We see her pick the dog up by its front leg and hurl it outside - an indication of her irritability and potential for aggression. Using his clinical skills, Akona engages her in conversation eventually getting her to agree to go to the mental health clinic in Site B (within walking distance of her dwelling). We end our visit after making arrangements to come again the following week to complete the interview. On the subsequent visit we find out that Noluthando had not yet been to the clinic. She is floridly psychotic and we make a referral to the psychiatric clinic where she is put onto anti-psychotic medication. Over time the result is a significant, positive change in her behaviour. However, there are important questions at stake about heredity of certain psychiatric disorders and the long term implications for the children of being raised by a mentally ill mother and grandmother.

Akona and I drive some distance reflecting in silence before we are able to talk to each other. (On occasion, harrowing experiences in other households left us both unable to debrief immediately and we had to let a couple of days go by before we were able to talk about our feelings and impressions). We find a safe and quiet spot to park the car and, with the tape recorder on, we discuss our observations. I interview Akona on the interview seeking to uncover his spontaneous understanding about aspects of the research questions that have arisen from his dialogue with Dorcas. We note aspects that need further investigation and when indicated, we follow up on referrals, for example calling the clinic sister to ensure that the baby and daughter receive medical attention or fetching a household member and taking them to the

hospital, the court, the police station or some other government office.

Over the next couple of days I write notes in my research journal, read a variety of relevant books and journal articles, label the tapes and deliver them to the translator/ transcriber I have contracted for the task. I brief him to make notes about his reactions to the interview during the translation and transcription process. When I receive the tapes back from him, I interview him about the process. He indicates which Xhosa words were difficult to translate directly, confesses laughing at some instances of psychotic talk (instances that Akona managed to contain during the interviews because of his professional insight and training) and feeling distressed by some of the stories. I spend some time debriefing him and reiterating our joint commitment to confidentiality. I read through the transcripts, make notes for follow up questions at subsequent interviews and begin to formulate my emerging understanding of household dynamics as these pertain to the research question(s). Whenever possible I discuss experiences, ethical dilemmas and theory in practice with my research colleagues thereby broadening my understanding.

3.5 CONCLUSION

In this chapter the theoretical stances and research procedures used during Phases 1 and 2 of the PDO study were described, justified and differentiated. Particular vigilance about issues of power and interpretation in the cross-cultural research context was highlighted. The use of socially responsible research ethics was explained and approaches in dealing with dilemmas in an ethical manner were highlighted. A brief vignette was used to describe the challenges that the study locality posed for selecting and implementing appropriate research methodology. The next chapter presents and discusses findings from the cross case analysis. It details the costs of psychiatric disability to poor households in relation to the impact of illness behaviour on occupational performance and describes the strategies within everyday occupations that were used by the disabled person and his/her household to deal with poverty and psychiatric disability.

CHAPTER 4: ACROSS CASE FINDINGS AND DISCUSSION

4.1 INTRODUCTION

The first objective of this study was to profile each of the five psychiatrically disabled informants in the context of their household structures with reference to their occupational and health history. Due to length constraints the detailed findings of this objective are not presented in this report[1]. This chapter presents and discusses the findings of the cross case analysis that addressed the second two research objectives: to identify the costs of psychiatric disability to households in relation to the illness behaviour and occupational performance of the disabled person and to identify the strategies within everyday occupations that were used by the disabled person and his/her household to deal with poverty and psychiatric disability. Following Stake (1995), categorical aggregation occurred through deductive analysis of the data. Codes speaking to direct and indirect costs and particular strategies for dealing with poverty and psychiatric disability were grouped together and aggregated into cost or strategy subcategories which were in turn aggregated into categories that aligned with conceptual constructions of disability (impairment, activity limitations and participation restrictions) (WHO,2001a) [2] and the basics of occupation (Nelson and Jepson-Thomas, 2003). In so doing, the tacit factors that influenced and operated within the basics of occupation such as motives, functions, goals, impacts and outcomes were foregrounded[3]. The subtle intrapersonal and social forces that shaped how poor households and persons with psychiatric disability living in those households coped with their circumstances and how they viewed, orchestrated, drew meaning from and attributed purpose to the everyday

1 The summarised findings of the first objective are presented in the Chapter 3: point 3.3.6 and in Table 7 on page 72, Appendix 3 contains a summarized description of each participant's health history. Findings from the first objective with respect to factors impacting on participants' occupational performances are also reflected in the current chapter.

2 Only costs incurred as a result of psychiatric impairment and disability are reflected here. In identifying these costs, attention was paid to codes that addressed (a) the financial and social antecedents of illness behaviors, (b) the illness behavior itself and (c) the financial or social consequences of the mentally ill person's actions. These codes were sub-categorized into meaning units that addressed either (a), (b) or (c). The sub-categories were in turn categorized into direct financial and indirect socioeconomic costs. In identifying strategies and stances, attention was paid to codes that described actions taken or attitudes that were adopted to manage events that threatened the welfare of some or all of the household members in terms of poverty and psychiatric disability. It could be argued that the strings of short quotes lack depth because they are not presented with a description of context nor are they individually followed up, explored or elaborated. Context was addressed in Chapters 2 and 3. Informants were also not able to provide thick descriptive narratives (see Chapter 3, footnotes 68 & 69, page 84)

3 Refer Chapter 2, Figure 1, page 21 and Table 9, page 122.

things they did become clearer in this chapter[4].

4.2 THE DIRECT AND INDIRECT COST BURDEN OF PSYCHIATRIC DISABILITY TO POOR HOUSEHOLDS

The cost burden of illness has been defined as "expenditure in seeking treatment (direct costs), production and income losses (indirect costs), related coping strategies, and their consequences for the household livelihood in terms of indicators such as the number of workers and working days, asset portfolios, income and food consumption levels" (Scoones, 1998, cited in Russell, 2005, p. 278). McIntyre and Thiede (2003) point out that a household's ability to cope with illness costs, in terms of their access to strategies and the affordability and sustainability of these strategies, is linked to vulnerability and resilience and the type of illness with which they have to cope. Psychiatric disorders[5] lead to particular forms of vulnerability[6] and require particular forms of resilience[7]. Serious mental illness gives rise to material and emotional costs ranging from debts and material losses incurred during psychotic episodes to socio-emotional costs associated with living in cramped spaces, day in and day out, with the unpredictable, irrational and sometimes obnoxious or violent behaviour of the mentally ill person. Psychiatric disability also introduces a particular social dynamic into the

4 The complexity of occupation in relation to the disabled person's functioning in and beyond the household is described in the next chapter. It illustrates the multiple layers of action, reaction and interaction happening in response to the illness behaviour and the urgency of daily survival experienced by the disabled person as a contributor to the livelihood of the household. Bolt and Bird (2003, p. 3) point out that unitary models of households which emphasise sharing, altruism and co-operation in securing a livelihood are being replaced with collective models that include the possibility of co-operative and non co-operative negotiation, bargaining and conflict. Instead of household unity, there exist many voices, gendered interests and an unequal distribution of resources. The point being made here is that the disabled person's occupational performance is intimately connected and interwoven with that of other household members; everyone contributing in one way or another to the economic fabric of day to day subsistence.

5 Psychiatric disorders (medical perspective) or *phambana* (cultural perspective) provide different interpretations of what is transpiring for (and by) the person whose behavior is deemed problematic.

6 See Chapter 2, point 2.3.4, page 41. Meikle (2002) defines vulnerability as the susceptibility of individuals, households (and communities) to sudden shocks or longer term stresses imposed by changing economic, environmental, social or political circumstances. The data from the cross case analysis suggests a particular form of vulnerability associated with enduring mental illness operating at the cusp between the individual and the social. The unpredictable, irrational and sometimes violent behavior of the (untreated) mentally ill household member rendered the individual and his/her immediate household susceptible not only to enduring forms of psychological stress but also to community backlash such as stigmatization or (perceived) curses. Here vulnerability was linked, in part, to ignorance about mental illness, fear of the unseen realm and inadequate mental health services.

7 See Chapter 2, point 2.3.4, page 41. Resilience has three defining characteristics (Berkes, Colding and Folke, 2003, p. 13). Firstly, the amount of change a system can undergo and still retain the same controls on function and structure (in this instance the change required by the household in accommodating the mentally ill person's illness behavior); secondly, the degree to which the system is capable of self organization (in this instance the strategies and stances used to deal with poverty and disability) and thirdly, the ability to build and increase the capacity for learning and adaptation (in this instance the adaptive capacity of the individuals concerned evidenced in their occupational performance) Resilience was compromised when the mentally ill individual was medically untreated; socially unsupported or unable to respond to or make use of psychotherapeutic (including cultural) intervention (assuming it was available, relevant, accessible and affordable).

cost burden that households with a mentally ill member have to absorb due, in part, to the fear, stigma and cultural sanctions associated with illness behaviours[8]. The findings suggest that the social fall out following a public psychotic episode or associated with enduring psychiatric stigmatisation compromises the household's (and the mentally ill member's) participation in economic opportunities. The sociocultural dimensions of occupational form become strained or restricted as people shy away from relating, bargaining, trading etc with affected individuals and, by inference, their household. In short, prejudice operates in occupational form and places additional demands on the adaptive capacity of disabled people. This is illustrated in greater detail in the next chapter.

Figure 4 depicts the costs associated with psychiatric disability[9]. Direct economic costs refer to those instances where some outlay of money was incurred as a result of the index person's illness behavior. Indirect socio-economic costs refer to those instances where reported social exclusion or participation restrictions occurred either for the mentally ill person themselves or for their immediate household as a consequence of the illness behavior. The interaction between impairments, activity limitations and participation restrictions in creating or exacerbating the disability status of participants is reflected in the two halves of Figure 4 (discussed in Chapter 2, point 2.4, page 50).

8 The effectiveness and efficiency of a household's economic survival is linked to the (in)stability of its social networks (Bolt and Bird, 2003). The tolerance of the network was compromised when the mentally ill person acted out during untreated psychotic episodes by destroying property (eg.Fuzile, Vuzi) or when the mentally ill person's behavior was inappropriate or obnoxious such as running around naked or acting strange or being belligerent and quarrelsome (eg. Dorcas, Sesetu).

9 Distinguishing between psychiatric disorder and psychiatric disability foregrounds different social dynamics that influence human occupation in the context of chronic poverty. The former pertains to the impact of illness behavior on household costs and the strategies they use in dealing with poverty and disability. The latter pertains to the impact of occupational form (ie. the sociocultural sanctions imposed on the mentally ill person and, by association, the household) on occupational performance. Costs and strategies arose from and were embedded in social processes that determined the distribution of influence and resources within and beyond the household.

Figure 4: Costs associated with psychiatric disability[10]

4.2.1 Findings: direct costs of psychiatric disability

Economic researchers consider the living costs[11] associated with treatment seeking as indirect costs to households (Russell, 2005). Households in this study however reported direct **living costs** as a result of mental illness. *"... people with mental illness have lots of needs ... they must eat before taking their medication...and then they eat a lot more than usual ..."; "... when his illness comes and he has an episode he will open the things in the fridge with a knife and will want to eat everything at once. If you buy something and he wants it he will just take it ... he eats too much ... we buy more food now ..."; "... he always complains now that he's got nothing like underwears, clothes, shoes ... compared to when he had an income but I look after him and buy everything that he wants ..." ; " ... I decided to call the cops to take him to hospital because the taxi is too much ..." ; "... when I was sick, the taxi was hired ... it drove around from doctor to doctor all night until I was taken to V (mental institution) ... it cost a lot ...".*

Maintaining communication with the living-dead (ancestors) also incurred **living costs.**

10 The categorical aggregation depicted in Figures 4 and 5 was developed by Duncan and Mbombo (2006). Akona Mbombo was my research assistant and co analyst of the costs and strategies data subset.

11 Living costs here refer to subsistence needs eg. food, shelter, clothing, transport, fuel

Households were particularly diligent in keeping burial society fees up to date and ensuring that the mentally ill member had access to culturally prescribed practices for protection and healing[12]. *"... during my illness and circumcision there were many things I did not do as the result I didn't go well on other things ... if you still owe some customs your things won't be smooth. So your ancestors will be cross for you because you were not introduced to them so they will make your life complicated ..."; "... he struggles to give the finances for the burials but he must pay ..." ; "... all my people were buried using the disability grant ... I would speak to the burial society's organiser and explain to them that I will pay them in instalments using the disability grant till my debt is paid up ..."; "... the problem is labola (bridal dowrie) ... I still owe that ..."* .

Habit costs[13] included the habitual purchase of alcohol, over-the-counter medication, nicotine, marijuana or other substances to self medicate reportedly to numb the senses in the face of enduring hardship or to have something to do to while away time. The tranquilising or stimulating properties of these substances reportedly helped people cope better with their circumstances[14]. The mentally ill household member was not the only one in the household (ab)using substances. *"... it (alcohol and dagga) makes my troubles go away ..."; "I buy additives of treatment which could help keep me fit, healthy and have stamina like multivitamins and anti-stress tablets..." ; "... when he relapses he smokes a packet in a day ... money would be wasted on alcohol and sometimes there is no money for the entire month for groceries ..." ; "... then if I have maybe R4 left I will go buy some beer ... my favourite is African beer ... if I ordered a bucket of beer please do not disturb me let me finish the whole 5 litres ..." ; "... he smokes excessively and spends lots of money as I buy the cigarette carton (R120) monthly but it only lasts 3 weeks... now I have to take from the business money to keep him calm ..." ; "... she uses smokes and alcohol too much ... she is always drunk ...".*

There were two sources of **treatment costs:** those incurred by attending public mental health services and those associated with seeking healthcare from traditional healers. Besides

12 Cultural practices involved expenses such as the purchase of an animal for sacrifice, paying for relatives to travel from or to far off destinations to attend ceremonies; hosting a feast in accordance with ancestral requirements and paying burial society fees (a proper burial ensures smooth transition into the afterlife for the deceased and acceptance by the living dead for those who remain behind) (Guma, 2004).

13 In the occupational science and occupational therapy literature habits refer to relatively automatic, repetitive patterns of human behavior that constitute routines or repeatable, predictable ways of acting (Christiansen and Townsend, 2004, p.4). Some habits are considered to be occupations. In this instance they do not refer to occupations but to patterns of behavior linked to substance (ab)use.

14 Swartz (1998, p. 230), discussing the role of drugs, alcohol and psychotropic medication in the onset and management of psychosis, suggests that "unless we know the social meanings of drugs and people's theories about how they affect their lives, we will not be able to help people in the best way possible. The cultural study of drug use spans the boundaries of biology and psychology, physiology and culture".

income lost by carers taking time off from (in)formal jobs to attend to the needs of the ill person, households reported that transport generated the biggest cost. When the illness behaviour became particularly bizarre or violent during the night or over a weekend, easy access to health clinics within walking distance of the household was of no use to caregivers. The household would incur taxi fare costs (at increased after hours rates) and would have to travel further distances to medical emergency units at provincial hospitals because local clinics only offer maintenance treatment, operate during limited weekday hours and do not deal with after hours psychiatric emergencies. *"…I have not received any assistance from the community except taking him to the hospital when he relapses by calling the police to fetch him at that time…" ; "…There are so many needs that we need to take care off so that you do not become a burden to other people. Clothing needs, illness related needs and sometimes you are even forced to take him to a special doctor… The special doctor costs R180.00, the special doctor. When you revisit for an injection you pay R80.00. R80.00, that's only for the injection…."*

Seeking treatment from traditional healers incurred direct costs that differed from those linked to seeking treatment at public health services. Firstly, the fee exemptions that exist in the public health service were not available in seeking traditional health care. Although traditional healers were reportedly flexible in terms of re-payment plans, they tended to be very expensive. Secondly, households incurred travel costs to access the services of particular traditional healers who lived in places of tribal or clan origins (for example rural Eastern Cape) as they were deemed to be "*more powerful*". The further the person travelled to receive guidance from a well known traditional healer was considered evidence of a wide social network and therefore social influence. Travelling to consult a renowned traditional healer reportedly sent a tacit message (such as retaliation or protection) back to those who were believed to have caused the problem. The costs were however not always seen to be worth the outcomes. *"… the poverty would not have been so bad if she was not ill … we have to divide the income to take her to African healers …" ; "… the evil spirits are those things like animals that affect your mind … she ate this thing, it is inside her … she can go to traditional healer to take that off because it is not her illness, it's just something that is put by someone else … She must wait until I have money to take her to the traditional healer to take that poison out … African healers charge sometimes R200, others R300 …" ; "… before I go to bed I usually use my traditional medicines to drive away evil spirits …" ; "… I took him to the traditional healers (in the Eastern Cape) and I wasted my money as I don't even have a cent left …he is still not better…"*

Impairment costs were incurred due to mental instability. Income was lost or foregone as a result of decreased functioning. Most of the index participants had held unskilled jobs at some stage in their life, for example domestic worker, dairy worker, bricklayer, gardener and factory worker. They lost their jobs or were unable to secure permanent jobs either due to illness, general retrenchments and high unemployment or unregulated labour practices in the informal sector (some were retrenched at the whim of employers when they became ill)[15]. Physical components such as low stamina, energy, endurance and physical strength; mental components such as poor problem solving, impaired memory and restricted insight ; affective components such as fluctuating mood and conative components such as reduced volition and motivation influenced whether individuals worked on any particular day or not, whether they felt in control of their business or not and whether they pursued one task rather than another to meet the challenges of daily survival[16].

"... I even lose all my grant payment because my memory goes ..."; "... I don't have power anymore ... I can't work anymore and even if I found a job they usually dismiss me as they say I am weak ... it's not that I cannot find work because I can, it's that I cannot perform..." ; "... there are too many considerations to make such as she cannot walk too fast, she cannot walk behind because she can fall and have a seizure ... I no longer have enough strength or endurance for that kind of vigilance and she also has low energy levels so I do not like it when she goes with me to collect cardboards because she gets sick in the middle of the job when she works too hard so we lose money that way ..." ; "... .sometimes when she is sick she takes the stock to use at her home ... she reduces the quantity so that you are unable to reach the target sales ... so this leads to you trying to run a business and losing motivation ..." ; "... when he was still fine he was very diligent but now he is unable to do anything ... I would love to go into a small business sewing things but because he is ill I am unable to do such things because I have to look after him ..." ; "... when he got his grant money he bought a watch for R800 and we had no food that month ...". (lack of insight and judgement during manic episode).

15 Employment equity positions only apply in the formal labour market.

16 Examples of impairment costs are highlighted in underlined italics in the quotes

Damage costs[17] were incurred as a result of violent illness behaviour resulting in loss of material household assets. Debts incurred by damaging neighbours' property often took a long time to settle, placing a strain on limited material resources[18]. *"... he is really destructive when he is ill ... he burnt my house and the bed ... he almost burnt the house down twice ... the other time when I bought groceries he burnt it all ..." ; "... he would wake up early and go into the streets and shout ... he would throw stones to the windows and put fire by cars" ; "... he broke my tea-set that was R1200 ... he broke them only after three months that I bought them ... he burnt our bed ... even the damages from December when he burnt my belongings can reach up to R5000..." ; "...if he damages other people's property I need to cover those costs ... he smashed windows of cars parked in the street ... I pay the debt bit by bit ... I spent roughly R500 already on his debts from his illness in December ..." ; "... her illness affects us very much because she refuses treatment ... she seldom takes her medication ... then she is violent and that makes the family suffer losses ...".*

4.2.2 Findings: indirect costs of psychiatric disability

Indirect costs were incurred in relation to the impact of the mentally ill person's behaviour on the social matrix within which the household functioned. Social sanctions operated both internally and externally to the dynamics of the household thereby undermining the social capital[19] they relied on for survival. Social capital, operating according to sociocultural beliefs and practices, is an important component of occupational form (Nelson and Jepson-Thomas, 2003). Most occupations draw on elements of form that pertain to the social. When this is compromised due to social stigmatisation of illness behaviour, the other basic components of occupation are affected. In short, the indirect costs of psychiatric disability directly influence occupation because a reciprocal relationship exists between occupational form and occupational performance as is illustrated in the following findings.

17 The behaviors described in the quotes reinforce the stereotypes held about mentally ill people. Since psychiatric disability is situated in social prejudice, it could be argued that mentally ill people who behave irrationally or violently contribute to their own stigmatization. An appreciation of the organic basis of mental illness however suggests that this negative social consequence does not necessarily lie within the power of the individual to address. Access to treatment and public education are indicated. It must also be pointed out that the difference associated with disability was reportedly not an issue in poor communities: everyone was in the same boat whether they had a health condition or not.

18 According to Grant (2000), debt changes relationships with creditors and can result in undesirable consequences, including harassment and paralegal action as well as provoke feelings of fear, anxiety, shame and bravado. The route out of debt can become an "all consuming problem that casts a shadow over sense of self, identity, and mental health as repayments swallow up what little money does come in" (*ibid*, 2000, p.235).

19 Social capital refers to the social networks and associations in which people participate, and from which they can derive support that contributes to their livelihoods (Ellis, 2000a, p.8).

The demanding, erratic, strange and sometimes frightening and violent behaviour (during psychotic episodes) of the index person incurred well-being costs for members of the household. The socio-emotional environment in the home affected the perceived well-being of its members. Intra-household dynamics were fraught with tensions and contradictions that influenced people's daily functioning. Key informants reported that living with and caring for a mentally ill person was very draining and impacted negatively on their energy levels, mental well-being and subsequent productivity. Household members rationalised their hostile feelings towards the mentally ill person by suggesting that, as the source of a regular income in the form of the disability grant, they were willing to tolerate his /her objectionable behaviour. The index person, in four of the five households, showed some intellectual insight into the negative effects of their illness behaviour on the emotional climate and ultimately the finances of the household. *"... we are not on the same track or sleeping with the same blanket*[20]*... if we were we wouldn't be struggling under poverty ..." ; "... it makes me feel sore in my heart because her disability combines with poverty and when I think of the poverty, the illness also comes up and it overwhelms the mind ... the poverty you learn to live with, my main concern of pain is the illness." ; "... the poverty made the illness worse because we think about surviving too much ..." ; "... I promise you there would be no poverty at all and I wouldn't be on poverty if he did not have this (mental illness)..." ; "... its very painful ... these people (the mentally ill member) affect you because of their illness ... you have to worry and care for them, you don't find much enjoyment ... sometimes you find yourself feeling the same as them because of the things they take you through ... we cannot enjoy life because he is ill ... we only look to the grant for support now ..." ; "... I am suffering very much (looking after two disabled adult children) but I've managed to cope under the situation with the help of the grant even though at times I almost lost my mind ..." ; "... the only thing as a household we can do is stand together and assist each other but she (disabled person) is unable to assist and work with us except getting babies all the time and we shout and tell her to get contraception because you keep getting these babies and they expose us to more hardship. Now she is pregnant again (fourth child) and she is affecting our mentals, we worry because we know that the baby will become our problem ..."*

Social standing costs resulted from the responses of people in the community, either towards the mentally ill person directly or towards the household in general impacting, in subtle

20 Cultural idiom for unity

ways, on their access to income generating opportunities[21]. "*... here your involvement depends on who you know as community members prioritise their friends ... like the street cleaning project where we could get employment, only my neighbours who have assets were taken and I (disabled person) ended not being employed...this gives me dynamics (social tension) ...*" ; "*... I feel valueless ... when people are looking at me they see I have got nothing and they can read me because I am not well and I don't like it ...*" ; "*... when she (disabled person) has money she is able to buy the insides (intestines) to sell them but people do not want to pay her because she has had misunderstandings with them ... people have jealousy ... some people can be amazed or frightened by her behaviour ... and when she comes to collect her money they always tell her stories ... so I advised her to first solve her problem with them then she can be able to do money ...*" ; "*... they know here in the community that I am not well so its hard for me to engage myself in social activities ...*" ; "*... people used to help each other but now people are cruel and usually when people help you they expect gains and you are aware that there are no gains that you can offer and then it is better not to seek assistance ... it is not easy to trust people these days as they easily turn against you but in the olden days we were helping each other especially here in the townships ...*".

Cosmology costs[22] refer to the tacit socio-economic repercussions of breaching cultural observances. These concerns weighed heavily on participants who, for financial reasons, were unable to meet their traditional obligations. Since belief systems also directs social roles including gender relationships, particular costs were incurred as a consequence of patriarchy. Abusive male behaviour, including habits that depleted scarce resources, was not confronted by women for fear of further abuse. "*... traditional customs or celebration of umgidi (circumcision) ... we did not do them because of scarcity of money ... if you still owe some customs, your things will not go smooth ... so your ancestors will be cross for you because you were not introduced to them so they will make your life complicated ...*" ; "*... difficulties of*

21 Yen and Wilbraham (2003a,b), describing the pathogenic constructions of envy and jealousy in impoverished communities, suggest that the 'good things' that are assumed to exist are, in reality, shaped by complex social norms, meaning-making practices and ideologies that determine how resources are distributed. While social capital is often described in positive terms, its contribution to poverty alleviation is in reality quite limited and ambiguous. Economic vulnerability "feeds into - and its other impacts are often amplified by - the vulnerable, stressed, power-laden and conflictual nature of the social networks on which individuals and groups rely for identity, survival and dignity" (Du Toit, 2004, p. 11). Dependency in poor communities is high, employment opportunities low and income from grants and other informal income activities restricted so that the socio-economic resources that are shared through networks become depleted very quickly. In short, there is only a limited supply of material and psychological goodwill doing the rounds. This implies a restriction of occupational form which in turn affects the scope of occupational performance (see Chapter 2, footnotes 46 and 57).

22 Cosmology refers to a metaphysical worldview ie. people's conceptions of reality, their position and purpose in the universe and their relation to others and the environment including their understanding of illness and well-being (Mkhize, 2004, p.35). African cosmology (not a singular phenomenon across indigenous groups) generally informs people's sense of time, space, causality and existence in relation to a hierarchy of beings (*ibid*, 2004, p.40).

life are customs because you have to follow them and maybe you dreamt [23] *about something and then you must do it … you have to follow those things … if it was shown to you, you are responsible … you cannot refer it to someone else … you can call all your relatives but you must be the one who addresses it …"; "… alcohol is viewed like a social engagement for men and if that was taken away from me I will feel like women have defeated me … (It will be) like losing identity as a cultural being in my social circle …" ; "… my father hated too much for us to visit other homes because he said when that family dishes they will dish a separate plate for you and maybe it's the time they put poison … because they can see you are so good for your family (brings in a grant) and you are the person your family can lean on …".*

Having a disability grant was a point of envy, contention, bargaining and social status. **Creditworthiness costs**[24] were linked to the loss of perceived privilege and social worth of the individual in receipt of the grant for extending credit, incurring debt or making debt repayments. Having a grant also led to the reckless accrual of credit which, unchecked, quickly outstripped the grant amount setting in motion a cycle of debt which households had difficulty reconciling. *"… they tease me and tell me I am government property because I receive a grant … they say I do not depend on the casual job like they do because I have something on the side that assists me while they do not have this luxury…" ; "… my wife enriches herself with my grant … it's like she is the one who gets paid when I receive the grant … she chose me and agreed to be in marriage with me … now I am ill she has the full obligation of a wife to take care of me… the thing that makes me angry is she is taking advantage of this … its like she has won the lotto.." ; "… if I can labola*[25] *everything will be fine … I will have credit if I can get grant and a wife … I will have status in the community even if I am ill…" ; "… I picked up manipulation as most community members knew that I was poor and would only give me things like small basins of sugar … and on the side I had these starving children … I had no credit with them …" ; "… you see the thing is we eat our credit … we end up having to eat the very same meat we are supposed to sell … my business is not growing because I use the same money I get from selling to buy other things like what he (disabled person) needs…" ;*

23 Meaning that the living-dead (ancestors) give commands in dreams.

24 Creditworthiness refers to having credibility as a reliable lender and borrower of cash and kind. Here creditworthiness was compromised by the social stigma associated with psychiatric disability. Wilkinson-Maposa et al. (2005, p. 49), in a study of the philanthropic practices amongst the poor, found that "money that is borrowed from friends is normally paid back without interest. Usury amongst friends is strongly discouraged. What is accumulated is a sense of trust. Friends who pay back at agreed times accumulate greater creditworthiness". They point out that "a high level of clarity exists on who one does not lend to or borrow from: people who are untrustworthy, who you are not on good terms with, who are healthy but lazy, people of dubious character and people who waste money on alcohol and drugs" (*ibid*, 2005, p. 40).

25 Pay bridal dowry.

In summary, psychiatric disability[26] exacerbates the financial burden of chronically poor households because it erodes scarce material resources and places strain on social networks that are relied on for survival (Goudge and Govender, 2002). It influences the physical and systemic resources available for the performance of occupations and creates a particular set of socio-economic circumstances that influence the occupational form[27] within which household members have to function. In the context of chronic poverty, the "environment-as-a-whole" is characterised by deprivation. While psychiatric disability compounds deprivation, it may be argued that deprivation itself creates conditions which compound psychiatric disability. While it is difficult to establish reciprocal causality between psychiatric disability and chronic poverty, the impact of both on the basics of occupation can be identified. In the next section, the practical and attitudinal strategies used by the five households in this study to deal with their circumstances are described.

4.3 STRATEGIES USED BY POOR HOUSEHOLDS IN SURVIVING CHRONIC POVERTY AND PSYCHIATRIC DISABILITY

The households in this study adopted coping strategies[28] that offset the impact of poverty and particular forms of exclusion and marginalisation associated with psychiatric disability that they experienced in the context of a peri-urban informal settlement[29]. Households in poor communities cope with urban life through a range of strategies, including putting more family members to work, petty trading, avoiding basic goods which represent luxuries to them, increasing their household size, withdrawing children from education, constructing their own shelter, establishing patron-client relationships with local leaders, borrowing across the social network and reducing spending on food, clothing and health care (Hadad,

26 The compounding influences on occupation interfaces with disability at this point.

27 For definition see Chapter 2, footnote 13, page 21. The economic dimension is not reflected in this definition of occupational form. It is suggested that it should be.

28 Sauerborn, Adams & Hein (1996) define coping strategies as a set of actions that aim to manage the costs of an event or process that threatens the welfare of some or all of the household members. The type of coping strategies that poor households with a mentally ill member adopted depended, in part, on their ability to absorb stigmatisation and to use the economic leverage introduced by the disability grant. Often in a better off financial situation than their neighbours, the disability grant increased the bargaining power of the household in relation to the illness behaviour of the mentally ill person.

29 The strategies used by the study households pertained as much to their general struggle for survival as they did to dealing with the mental illness and psychiatric disability. Coping with poverty and coping with psychiatric disability were, in effect, conflated experiences of dealing with deprivation, adversity and enduring financial hardship. Households had to deal with numerous health and social problems besides having a mentally ill member for example HIV/Aids, alcoholism, intellectual disability, incest, rape and domestic violence (see quotes). The blurring between general livelihood strategies and those specifically deployed to deal with the economic implications of the disability could not be isolated because, as Aliber (2001b) points out, disability becomes superfluous in the bigger scheme of chronic poverty and unemployment; it is assimilated into the economic burden of everyday life and becomes indistinguishable from other shocks and misfortunes amidst the grinding hardship of life at the margins.

Hoddnott et al, 1997; Sauerborn, Adams & Hein, 1996). The research households used a range of similar strategies with the mentally ill household member either eroding or facilitating household efficiency depending on whether the health condition was in remission or not[30]. The strategies depicted in Figure 5 on page 112 were either extrinsic/practical or intrinsic/attitudinal depending on whether the data code was interpreted as 'doing' something to alleviate poverty and manage disability or whether it reflected an attitude or 'being' stance towards the challenges of daily survival[31]. For the purposes of categorical aggregation of the data, extrinsic coping strategies were defined as objective actions taken by informants to sustain the economic viability of the household. Intrinsic coping stances were identified as tacit and attitudinal approaches; ways of 'reading', discerning and understanding what needed to be done at a particular point in time in order to secure the best possible strategic outcome in the interest of survival. The point being made through Figure 5 is that an understanding of the basics of occupation in the context of chronic poverty and psychiatric disability must take into account the urgency of survival that informs the over-riding script for occupational performance. While every occupation has inherent meaning and purpose[32] for the doer (for example, mending a garment may be gratifying in and of itself), it may also be motivated by the need for survival when particular conditions of deprivation prevail (for example the intrinsic strategy changes or adds another meaning dimension when it is the only garment you have to wear or when you have no money to buy another garment). In other words, the sub-text of occupational performance in the context of resource constrained occupational form is to "use and even seize control of time and space (or place)"[33] with the meta purpose of making ends meet in mind.

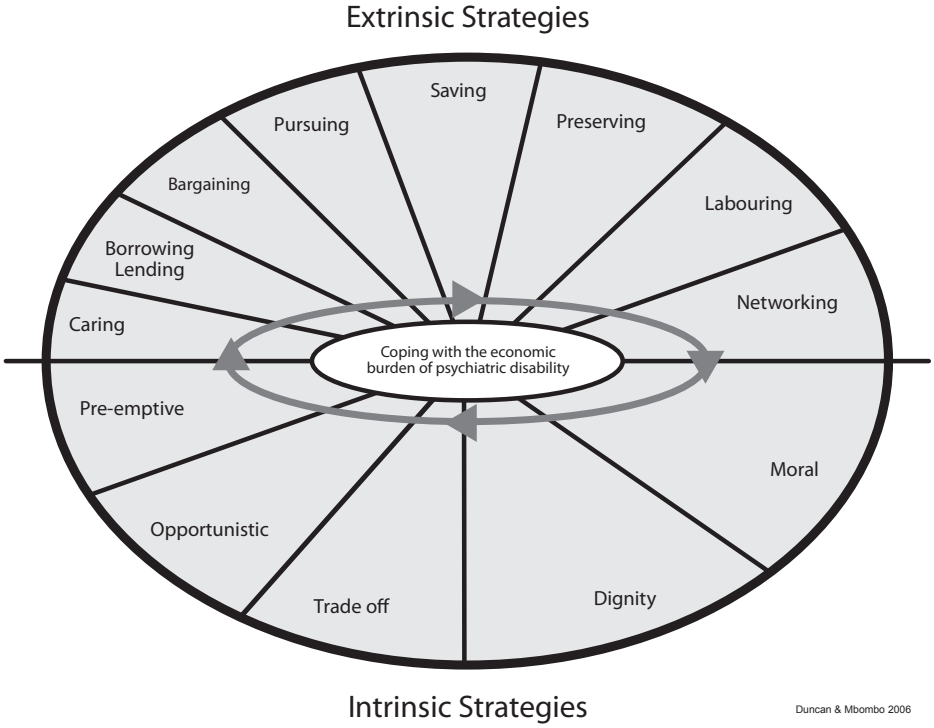
30 According to Ellis (1998), poor households and individuals adjust the mix of their coping strategies according to their emerging circumstances and the changing context in which they live. We observed multiple changes in each household over the years that we were engaged with them such as taking in foster children (Thumeka and Dorcas); adding a new room to a dwelling to accommodate an informal trading business (Vuzi, Siyanda and Fuzile) and joining a new church and, in so doing, reporting the development of a social network though which material deprivation was relieved (Fuzile and Siyanda).

31 The strategies depicted in Figure 5 are not exhaustive, they simply reflect those that emerged at a point in time during the study.

32 For definitions refer to Chapter 2, footnotes 15,16,17

33 Christiansen & Townsend (2004a, p. 2)

Figure 5: Strategies used by poor households in surviving chronic poverty and psychiatric disability[34]



4.3.1 Findings: extrinsic strategies

Caring[35] served two strategic purposes: as a source of income and as a means of building social capital[36]. Four of the five households secured an additional income from the child support grant. Children were taken in for reasons such as overcrowding in their natal dwelling, death

34 The categorical aggregation depicted in Figure 5 was developed by Duncan and Mbombo (2006). Akona Mbombo was my research assistant and co-analyst of the costs and strategies data subset.

35 Caring, as a form of helping, involved "an investment in social relations with an expected return" (Lin, 1999, cited in Wilkinson-Maposa et al., 2005, p. 102). Caring involved numerous occupations for example spending time playing with children, washing and feeding them and guiding homework projects. Wilkinson-Maposa et al. (2005) differentiate between material (for example money, materials and tools, clothes, food) and non-material (for example care giving, information giving, domestic help, emotional support, protection, manual labour, communication, transport) forms of help amongst the poor. These forms of help are offered vertically (from richer to poorer as in development assistance and charity) or horizontally (between the poor themselves) in response to imperatives such as lack of assets / commodities / funds, emergencies such as natural disasters, lifecycle events such as funerals and weddings and during times of development change such as money for school fees or starting a new business.

36 Lund (2006) argues that social security systems (for example child support and disability grants) tend to be designed around assumptions about the role of females as traditionally labouring in the home while male 'breadwinners' sell their labour in the marketplace. She points out that what the State and the formal private sector provides in welfare social security is but a fraction of the caring work that is done in society - the unpaid, non-market work performed mostly by women in people's homes. In this way women are active contributors to social development through the 'economy of care' which may be defined as the "economic costs and benefits of care, the division of labour involved in various types of care, and the contribution of care to economic growth and development" (Ogden et al., 2004, cited in Lund, 2006).

of the parent or no-one at home during the day to look after the child[37]. There were double edged spin offs to caring and helping strategies. Positive spin offs included socioeconomic benefits for the household while negative spin offs potentially affected the children involved. For example, in one case the girl child was expected to help with a new born baby so that the adult member (the psychiatrically disabled person) could go out to work. This child was taken out of school to fulfil menial household duties thereby potentially setting in motion pre-conditions for academic developmental delay[38].

"... there are two children that I care for and gain income through caring ... for my grandchild I get R200 and for my tenants child I get R150 as he attends preschool" ; "... I was given this child by my family because I cannot wash my clothes anymore so she is doing that for me... she does the shopping too and I am educating her, I am responsible for her [39] ..." ; "... she is getting grant for the children. With the money she just buy small groceries and takes the remaining one to her boyfriend who is always abusive ... if she is beaten up by her boyfriend she comes here and takes all that anger to the children and beats them up ... we (sisters) have to look after them but do not get the money for them ..." . "... my role is like that of the mother ... like last month my little sister was raped by my other sister's boyfriend ... I have to run around to take care of everything (finding money for transport to get sister to the doctor, reporting incident to police, paying someone to drive around the community to find the perpetrator, who co-incidently was 'hidden' by the older sister) ... the community helped me look for him ...".

Borrowing and lending involved asking for or extending loans in cash or kind from and to people who belonged to the social network within which economic and physical survival was vested[40]. As a strategy to deal with the costs of psychiatric disability, borrowing occurred in a tenuous interpersonal space of give and take, of trust and mistrust, of inclusion and

37 Lund (2006) points out that little is known about how decisions are being made in households about who applies to be the primary caregiver and therefore the recipient of the child support grant, but she suspects that the decisions are highly gendered by expectations of women's roles.

38 See Dorcas's case study, Chapter 5, Table 14.

39 She saw the purpose for caring as role training and induction (through role modeling) into cultural ways of being including gendered role expectations.

40 Observations during overnight stay in an informal dwelling: "It is very cold. The single light bulb flickers sporadically as the precarious electrical connections respond to the overload from multiple connections to a single source. There is a knock at the door. Someone has come to borrow some sugar. There is another knock at the door a while later. This time the person returns a garment that was loaned. S. tells me she must quickly go "next door" to pay back some money she borrowed. She tells me that she owes and is owed many small amounts; all of which she remembers to settle when she gets or needs money (excerpt from field notes: 6 May 2006).

exclusion[41]. The exchange of cash and kind occurred during occupational performance *"... if we do not have maize my mother would send us to borrow from other homes. She usually say that 'a person is a person by others' so that you can borrow something from other homes as well like they borrow from you ...if maybe we don't do this we will see suffering...."* ; *"...always look up for someone else ... don't fold your hand for that person ... if someone wants something from you and you have it, you must give it to him so that you too can live life ..."* ; *"... I go to my brothers ... they give me whatever I'm short of ..."*; *"... if he get sick I have to run around and borrow money ..."*.

Bargaining emerged as a particular strategy for acquiring marketable goods with which to keep small informal businesses afloat or to acquire material goods for subsistence. One participant said she quickly learnt that it is no good just begging for old clothes to sell; it was better to bargain or barter by offering people something in exchange, such as Tupperware or ornaments as this ensured some return of clothes on the investment of time[42]. One household made use of begging in times of dire need; bargaining with potential donors for discarded food or clothing. *"... even for me to get something to wear or eat I go around asking for second hands clothes or food ... we do not buy clothes from shops ..."* ; *"... she taught me how to barter.. how to use my disability grant to buy the Tupperwares and to exchange that for second hand clothes..."* ; *"...she does not borrow money, she just goes around looking for scraps (left over food, discarded fruit or vegetables) from neighbours and in the market place to feed her family ..."*.

Pursuing describes the relentless effort research participants put into following up leads for potential jobs, finding ways of bypassing the 'system' to avoid paying fees for public services such as train fares and being 'streetwise' and well informed about income generating opportunities circulating the local grapevine, although these did not always prove to be trustworthy. *"... even tomorrow I will wake up for hunting ... I hunt and hunt with my foot unless there is someone who will feel for me and give me R5 for a bus ... Sometimes I get a job, sometimes I don't and then I come back home with nothing ..."* ; *"... I came across this guy ... I explained my situation to him that the doctor refused my grant ... he then understood after much explaining and then he considered employing me ..."* ; *"... I wake up very early and go to the*

41 According to Wood (2003) poor people often opt for the slippery slide of dependency in exchange for security, choosing 'risk management in the present' over investment in the future. In their desperation to survive, they may incur debt in the 'here and now' to secure food and resources to meet basic needs even when this may result, in the long term, in dependency on exploitative individuals (for example loan sharks) or the erosion of goodwill.

42 These goods were purchased from wholesalers with whom participants reportedly established good trade relations, using part of their social security grants to secure bulk buy bargains for bartering.

farms in Paarl and stay there to save transport money …we targeted times when we thought there would be no securities and ticket officers at the train stations so we do not have to pay …" ; "… we walk the twenty kilometres to Mitchells Plein to hunt for clothes, that way we save money…".

Saving consisted of strategies to stretch the Rand such as bulk buying in groups and sharing products; being on the look out for shop specials (people would spend substantial amounts of time walking from retailer to retailer hunting for bargains, comparing prices etc in order to save a few Rand); joining an informal saving association (stokvels) and being judicious in the use of material goods. *"… she stocks on bulk because we are a big family…" ; "… I save in the stokvel (savings scheme) banking … maybe when my grant stops we have something…" ; "… so I want her (daughter) to do business like me (disabled person) so she can make a living … she must learn to buy in bulk … 10 kilograms not 2 kilos, 20 litres paraffin , not buy small things …" ; "… joined some money club here in the community where we collect money throughout the year and share it equally by the end of the year …".*

Preserving refers to the ability to make something out of 'nothing' ie. turning discarded objects into functional ones or finding ways to make produce last for longer periods of time. Interestingly, this strategy was linked to a number of committed occupations in households aimed at decoration, adapting the functions of objects to increase utility and other innovative cost saving environmental adaptations for example, one research participant, in an effort to save money to pay off a debt incurred by breaking things during a psychotic episode, plastered his room with newspaper and flour glue instead of buying paint. He was also adept at preserving social relations that would pave the way for getting casual jobs through friends. He stated that *"… not just anyone gets a job there … it depends on who you are, who you know, who you live with … I got the piece job because those people know me very well … I have a history with them … when I get there I do not just start working … you must first greet … first check it out…". Another male participant developed skills in mending clothes stating " … as a person you must be able to do anything by yourself … like this trouser I am wearing, if I see it needs to be sewed I do that myself so I can still wear it to save money …". Other participants were creative in decorating their home; finding transport and using available land for food production. "… the household has no furniture but we use crates for chairs and a makeshift trolley as a cart to fetch wood …" ; "… the patch of tilled ground had a small garden producing spinach and pumpkin. T. says she sometimes bottles produce that can be preserved…" ;*

Labouring involved sustained physical effort in maintaining informal income generating contracted occupations such as selling soap, sugar, sweets, cakes, cooked meat and clothes.

In the context of chronic poverty where almost everyone was unemployed, the disabled person's efforts to labour and trade were indispensable to the livelihood of the household. Disabled participants in this study did not perceive themselves more or less fragile than other people when it came to their ability to labour. *"... we are doing this hard labour together. We take ownership of the task ... we take these collections to the scrapyard to sell them there and that is how we make money to get something to eat ..." ; "... I get injections (anti-psychotic medication) but if I forget my date, I will get terrible headaches, sometimes I even forget my clinic card but they still give me my injection and then I am ready to go and trade my second hand clothes ..." ; "... I spend my day visiting friends, but they are not ill ... we enjoy ourselves listening to music and chat. They have a stand so I keep myself busy there by packing potatoes ... I want to keep my day going because I do not want to sit around and do nothing ..." ; "... I do piecework on the farms ... I sometimes labour during specific seasons; maybe I get work 5 months of the year ...".*

Networking involved building and maintaining an informal relational economy[43] that was central to the exchange of cash and kind. The network extended outwards from the immediate household members to distant relatives, neighbours to street level bureaucrats, shop owners to social groups such as burial societies and saving schemes. *"... I teach my children to take a collective decision about everything that happens around here ... one has to look for this and the other for that ... each and everyone of us finds something to do as a contribution to whatever needs to happen ..." ; "... we are friends because we sell clothes together ... she sells for me and I sell for her ... if one is busy or has a problem, the other one will sell for another one ... so I met my friend through that and we communicate like that ..."; "..... we buy the cutlery and Tupperwares at low prices at discount at a shop where we are regular customers. In December we get presents from that shop for being good customers ..." ; "....the community was giving out the food parcels they did not give her ... the council gave out the food parcels and they said Thabo Mbeki gave some food parcels for poor people but she did not receive it ...".*

43 De Swardt (2004) speaks about an informal relational economy in which kinship is only one of a complex range of social relations, affiliations, alliances and enmities that structure and are structured by informal exchanges of resources aimed at offsetting survival amongst the poor. Underpinning the relational economy are occupational performance skills such as the ability to manipulate the urban system to gain access to social services, juggle debts and obligations and managing risks by claiming membership of 'stokvel' groups (informal savings and credit schemes) and burial societies. People 'perform' being worthy recipients of welfare and 'curry favour' with gatekeepers and street level bureaucrats. They spend large amounts of time and effort into being seen by the formal apparatus of the State for example waiting in social grant queues and applying for documents and other conditionalities.

4.3.2. Findings: intrinsic strategies

The intrinsic strategies discussed here pertain to data in which participants reported adopting particular stances or attitudes in making sense of their circumstances and in thinking about what they had to do. They adopted intrinsic strategies and regulated their actions according to personal and cultural values that enabled them to make sense of everyday life[44].

Pre-emptive stances were adopted in anticipation of events so that productivity was preserved by proactively managing imminent set backs related to health, social events and household dynamics. Some participants were more 'forward thinking' than others. They made contingency plans in advance in terms of their fluctuating health and finances. They were able to anticipate potential consequences of health relapse and set mechanisms in place to pre-empt possible adverse outcomes. *"... when I return from hard work collecting cardboards, I can have an attack and I try to stay calm so that I do not become ill when I have to work again... I just sleep the whole time because I know I am about to get ill ... that way is an indication I am about to get ill and they leave me to heal ..." ; "... when winter rains come I request leave ... I become jealous of uMulungu (white person) because we all stand in the rain as his workers and he sits inside his car and never gets wet like his workers and that angers me ... so to avoid that anger so I do not get ill again I'd rather be off work ... anyway I do have the grant so it's not like there is much loss when I take time off during winter ..." ; "... when I am slowly becoming ill at work my indication is when I frequently quarrel with my colleagues ... I sometimes want to hit them and when they see that they remind me to take my medication because they know that calms me down ..." ; "... my so called seasonal work is affected because I have to leave suddenly to care for him so I choose to work sessions to be more flexible ...".*

An **opportunistic stance** demonstrated cunning in reading and interpreting situations or events as potentially income generating. It involved scanning the environment for objects, opportunities and materials that could be exploited for gain and recognising when a bargain

44 According to Wilkinson-Maposa et al. (2005) helping amongst the poor is underpinned by values such as 'ubuntu', solidarity, reciprocity, altruism, benefice, religion, trust, compassion / pity, guilt, jealousy, or obligation. A set of rules or conditions exist such as who and why help is given or received including fees paid, interest charged and the amount that is loaned. Not easily translated into English, 'ubuntu' conveys the idea that "a person is a person because of other people". Ubuntu is manifest in humaneness, mercy and respect for others and for life. Ubuntu is said to act as the cohesive element within African communities who share their resources, time and energy to meet personal needs and goals through communal life (Ndungane, 2003; Teffo, 1994). Ubuntu and communalism is a force in African lives that articulates cultural demands for group acceptance. While African communalism is portrayed as inherently holistic, hospitable, natural and loyal to ancestral traditions, it can have negative consequences when collective group pressure is applied to sanction individual behaviour. Amagqira (visited by household members on occasion during the study) are seen to be the spiritual custodians of ubuntu. They are consulted when cohesiveness and social integration is undermined by jealousy and envy (Masina, 2000; Yen and Wilbraham, 2003, a,b).

was to be had (even if obtained illegally). *"... sometimes I go hunting and I come across someone cutting his garden trees. I would go in but first ask for coffee and at that time she went in to make coffee I would continue cutting that tree and if she is satisfied with my job she gives me R20 ... so that is brilliancy ... to me that is the technique I use to get something on hand ..." ; "... even as I walk around and come across materials that we are collecting, maybe iron, wood or cardboard I pick it up and pack them here until there is enough to sell and make money ..." ; "... I look for bargains and sales ..." ; "... I buy that microwave for the business cheap from the thieves ...".*

A **trade-off stance** was adopted when 'playing to the audience for gain' was indicated; doing a favour or helping someone to bank goodwill in anticipation of trading in on it at a later stage or when bartering was required in order to secure material goods. 'Trade off' attitudes were sometimes viewed as manipulative, exploitative or immoral means of achieving security. *"... she uses her disability ... she agrees with her sickness ... that is the only thing that she is good at... to 'vat en sit' (to exploit) so she can get what she wants ... when the days are dark she knows we are the first people she comes to ..." ; "... when you owe something to someone you have to pay them back thinking about the future that maybe they will have to help me on something else later.." ; "... there is a lot of nepotism and corruption in community upliftment projects ... the people get their friends jobs ... that's how they get ahead ..." ; "... I asked uMlungu[45] for a piece job. He said he had nothing for me but I could do something for him for R50 ... I felt it was very little but because I had nothing I thought I might as well accept whatever offer because I needed soap, toothpaste and we needed food at home ..." ; "... she is surviving by asking money from men and by sleeping with these men ... I do not like that because she will teach her children what I am not doing ...".*

A **dignity stance** refers to the innate sense of pride and self worth that enabled participants to keep the indignity and dehumanising effects of poverty at bay. Poverty, shared by so many others around them, was nevertheless a private matter, something to be borne with fortitude and handled with determination. *"...I don't exactly want to take the poverty outside of the home[46] so I just keep working ... if you didn't get yourself employment you are a nothing, you are just a person ... if you can't go out and get a job then there is always something that you are doing with your hands to make you a somebody" ; "... the child who is poor must not look poor ... when she goes to school she must have lunch packs so she does not sit without food*

45 uMlungu: white person

46 Keeping the extent of the deprivation private; others must not know how bad it is.

and find herself impoverished even at school …" ; "… this the one thing that we just have to do … there is no other way out of it … I am collecting because of the embarrassment of begging … I don't ever want to have to beg …" ; "… the church has given us new life and dignity … we have peace in this house now and even my reputation and personality is different with people … I don't have friends that mislead me now … I just look up to God now … I even leave the house in good order now …".

A **moral stance** provided the cultural and spiritual value base from which participants operated, such as commitment to the family and clan ties, honouring parents, spirituality and self discipline. Syncretism featured strongly as households maintained a compound rather than single belief system in guiding their actions in the world. Besides adhering to traditional isiXhosa customs, four of the five households were members of Christian sects[47]. *"… I always set myself as an example to her and even ask her to look at my path, I tell her that if she can quit her addictions she can do many things, like me, she can see my efforts that I make and she can also make the same but she does not want to…." ; "… I take all my money and give it to my parents and stay there penniless and I don't mind as I know I didn't waste or throw it on the beer, I gave it to support the family …" ; "… one should never give up on your parents … when I get ill my mother looks after me, now I look after her by helping her get money… its my way of paying back …" ; "… in my suffering I would waste money as I was an alcoholic. But I decided to give myself to Jesus and now I can tell even a cent that I spend …" ; "… God puts me in this way of poverty … When I get those negative thoughts I look up to God for help because in the end I have to keep living and I ask him to set me free … God … when will you please take me out of this? …" ; "… God stood me up and got me out of all kinds of problems and suffering. So if a person can put faith on Him, He will free you on every problem that you come across with same as He did for me …".*

4.3.3 Findings: strategies interacting with the basics of occupation

Interacting with each other, the extrinsic and intrinsic strategies interfaced with the basics of occupation in terms of the *physical, structural or systemic factors* influencing occupational form; *motives* underpinning meaning; *functions and goals* underpinning purpose and *impacts and outcomes* informing occupational performance[48]. The point here is the inter-relatedness of necessary, committed, contracted and discretionary occupations for socioeconomic

47 According to Mkize (2004, p.34) "cultural meaning systems are always in dialogue with other bodies of knowledge. They are thus capable of undergoing innovation and renewal. This has been the case with independent Christian churches in Africa. These churches have successfully interwoven traditional African and Christian belief systems".

48 See Chapter 2, Figure 1, page 21.

survival[49]. For example, caring as an extrinsic strategy involved, amongst others, taking in a foster child. While being a contracted occupation, it also involved necessary and committed occupations such as bathing, feeding and dressing the child; washing the child's clothes; walking the child to school; playing with the child etc. An interpretive analysis of codes pertaining to occupational form revealed that the child, usually related by kinship, was taken in by the household for a variety of reasons such as the parents being deceased or unable to care for it; to assist the disabled person cope by providing practical help; to schooling the child (usually sent from the rural Eastern Cape) and to accessing the child support grant. The arrival of the child meant the need for space in the dwelling for an extra person; additional resources to meet the child's basic needs and remaining on a good footing with the social network[50]. Motives underpinning the meaning associated with caring ranged from altruism (for example Vuzi's mother, Thumeka, reported a spiritual commitment to fostering HIV positive children) to pragmatism (she also stated that the child care was a guaranteed way of increasing the disposable income in the home). Operating here were, amongst others, trade off and moral intrinsic strategies. The functions and goals underpinning the purposes associated with caring ranged from repaying social debts to securing access to a child support grant (as in Dorcas's case) while the impacts and outcomes of occupational performance associated with caring ranged from additional burden on the woman doing the caring (as in Dorcas and Thumeka's cases) to an additional source of labour in the household (older children performed chores as in Dorcas's case).

Drawing on cross case analysis, Table 9 provides examples of how intrinsic and extrinsic strategies may interact with the basics of occupation. It presents a selected occupation from different case studies and shows how a particular strategy may interface with the basics of that particular occupation. As mentioned previously, the point being made is that an understanding of the basics of occupation in the context of chronic poverty and psychiatric disability must take into account the urgency of survival that informs the over-riding script for occupational performance. While every occupation has inherent meaning and purpose for the doer, it may also be motivated by the need for survival when particular conditions

49 For definitions refer to Chapter 2, point 2.2.6

50 The tenuous nature of the social network is reflected in the following vignette. The Bekwa household was fostering a two year old girl child who was HIV positive and on ARV treatment. This meant that the child had to take her medication every day in order to curtail the development of AIDS. We found the household in distress one day. The child's mother had arrived unannounced from the Eastern Cape and had, according to them, "abducted" the child without taking her medication along. We were asked to take Thumeka to the police station to report the missing child. We found out later that the mother had returned to the Eastern Cape with the child because she believed the child was not being cared for properly. The child was no longer taking ARV medication.

of deprivation prevail. Poor people may be pre-occupied with more than the immediate demands of the occupation which they are performing; the gnawing concern for meeting basic needs hovers as a sub-text requiring vigilant use of a range of survival orientated strategies, irrespective of what is being done across the arbitrary categorisations of occupation.

Table 9: Strategies interacting with the basics of occupation

EXTRINSIC STRATEGY	EXAMPLE OF OCCUPATION	BASICS OF AN OCCUPATION (Nelson & Jepson-Thomas, 2003, p. 111)				
		FORM	DEVELOPMENTAL STRUCTURE	MEANING	PURPOSE	PERFORMANCE
		physical, systemic& structural features	abilities & acquired skills	ascriptions, motives & INTRINSIC STRATEGIES	functions & goals	impacts & outcomes
Caring	Fostering a child: parenting (mothering) activities & tasks eg. feed, dress, wash & nurture child.	Space in dwelling for extra person; resources to feed; clothe, school the child; social network	Bio-psycho-social performance components and adaptations eg. emotional resilience	For example trade-off & moral stances	Access child support grant Settle social debts Affirm social capital	Regular (monthly) disposable income; added burden on woman as caregiver, extra labour in h/hold
Pursuing	Hunting for a casual job.	Access to transport to job hunting site(s); social network (eg. word of mouth information re. job opportunities)	Bio-psycho-social performance components and adaptations eg. endurance, volition	For example, opportunistic & dignity stances	Obtain cash Maintain social network	Occasional disposable income to meet immediate hand-to-mouth subsistence
Saving	Shopping: bulk buying & sharing goods and fresh produce.	Access to transport Social & partnerships network (eg. info re. bargains at mega stores)	Bio-psycho-social performance components eg. stamina to carry goods, planning, calculating	For example, trade off & opportunistic stances	Stretch the Rand Secure staple food	Extended food security
Preserving	Mending clothes.	Access to second hand clothes Tools & materials	Bio-psycho-social performance components eg. hand function & sewing skills	For example, dignity stances	Cost saving	Increased utility of material resources & products
Labouring	Collecting glass & cardboard for recycling	Trolley; social systems at dump site (eg.competition for access to refuse)	Bio-psycho-social performance components eg. physical stamina to push, pull, carry	For example, opportunistic, dignity & moral	Obtain cash	Occasional disposable income to meet immediate hand-to-mouth subsistence
Networking	Attending church; 'stokvel' or burial society meetings	Sociocultural influences	Bio-psycho-social performance components eg. social skills; conflict resolution skills	For example, dignity & moral stances	Secure the future (long term): socially, financially, spiritually	Informal relational economy is maintained
Borrowing/ lending	Socialising with extended h/hold members & neighbours	Sociocultural influences	Bio-psycho-social performance components eg. social skills; conflict resolution skills	For example, pre-emptive & moral stances	Secure the future (immediate): socially, financially, materially	Informal relational economy is maintained
Bargaining	Selling produce from home (eg. soap, decanted oil & fuel, sweets, cooked food etc.)	Access to resources (eg. purchase stock, fuel to cook produce, storage space). Social network	Bio-psycho-social performance components eg. business, selling, bartering skills	For example, opportunistic & dignity stances	Secure the future (immediate): socially, financially, materially	Occasional disposable income to meet immediate hand-to-mouth subsistence

4.4 DISCUSSION

Two central organising ideas emerging from the cross case analysis form the basis of this discussion. The first focuses on the impact of structural form on occupational performance and argues that the direct and indirect costs of psychiatric disability are exacerbated by structural barriers in public sector services. The second focuses on the impact of sociocultural form on occupational performance and argues that esoteric beliefs and practices shape the meaning and purpose that people attribute to their daily activities, tasks and roles.

4.4.1 Impact of structural form on occupational performance

Health reforms at psychiatric institutions in South Africa over the past decade have led to deinstitutionalisation of large numbers of mentally ill people into communities with poorly developed social support services. Despite the much touted adoption of the primary health care approach, accessible psychosocial rehabilitation State services do not yet exist in all health districts[51]. Rationalisation of tertiary level health services has resulted in households having to absorb the direct cost burden of the daily living expenses of people who either have nowhere else to live independently or whose functional impairments, such as persistent thought disorder, avolition and mood instability, make it difficult for them to look after themselves[52]. Whether or not poor households are able to manage the behaviour of the individual, they are expected to 'get on with the job' of managing the needs of the mentally ill member. In the absence of adequate support services, households have, in effect, taken over the function of the State which paradoxically, is to alleviate poverty[53].

51 De-hospitalization policies, bed shortages at tertiary and secondary level hospitals and inadequate primary care crisis intervention for mental distress have, in effect, relegated psychiatric care to families, households and communities. The impact of deinstitutionalization policies on the lives of mentally ill people and their carers is particularly acute in the absence of adequate alternative community based resources and services. Non governmental organizations such as the Cape Mental Health Society compensate for community based service gaps left by the National Departments of Health and Social Development. Although the South African National Rehabilitation Policy (DOH, 2001) includes the provision of psychosocial rehabilitation and home-based care in its comprehensive care package, this is not yet extended to mentally ill persons who are still floridly psychotic when they are discharged from mental institutions.

52 Wilton (2004a,b) reports that carers experienced the greatest difficulties and stress in managing the negative symptoms of mental illness such as refusal to perform household duties, neglect of personal hygiene as well as positive symptoms such as bizarre behaviors. Zaidi (2003, cited in Mitra, 2005) found a positive correlation between extra costs imposed by disability and the severity of disability with direct costs averaging as much as three months of a person's annual income.

53 Patel and Kleinman (2003), writing about poverty and common mental disorders in developing countries, indicate that research confirms association between poor housing, overcrowding, feelings of job or income insecurity and the incidence of common mental disorders such as anxiety and depression. They point out that the experience of insecurity and hopelessness, rapid social change and the risks of violence and physical ill-health may explain the greater vulnerability of the poor to common mental problems.

Although the disability grant is intended to cover the living costs of the disabled person, in reality it is often the only steady income and means of survival for the entire household[54]. MacGregor (2006) points out that since the grant is only equal to about half of an employed person's income in the same community, the amount is hardly sufficient to subsidise one person, let alone an entire household. Shared across members of the household, grants are used to offset a multitude of household needs. Grant recipients are in an invidious position whichever way they turn; they are dependent on the household which, in turn, is dependent on them. MacGregor (2002, p.84) states that "given the difficulties associated with generating an income, the disability grant represented a very powerful tool to improve the well-being of persons with [mental] disturbance". The grant influences the disabled person's self image because s/he is seen to be a contributing and therefore important member of the household. Yet most disabled people are excluded from any hope of training or employment because of general unemployment, employer ignorance and prejudice and inadequate rehabilitation services. Their special needs, for example anxiety and depression management training and psychosocial support groups, are also not met. Even medication may be foregone because transport expenses are too much for the household to afford, the money intended for the recipient having been used to offset other household needs.

While the disability grant is an imperative form of social security for disabled people it becomes, in the context of poverty, a form of social security for entire households thereby limiting its intended benefits for the index recipient who, as primary provider, needs to maintain the sick role in the interest of household survival. In short, the needs of the disabled person are subordinate to the needs of the household. His or her primary role and/or identity is to 'be disabled' (Duncan et al., 2006). The adoption of a disability identity as an economic strategy has significant implications for the outcomes of rehabilitation because of potential conflict of interest between health service providers and recipients. The former are interested in reducing disability by remediating impairment problems, rehabilitating activity limitations and facilitating inclusive social participation and equal opportunities[55]. The latter are forced by circumstance to use disability (consciously and unconsciously) as a means of

54 The uptake of grants in Khayelitsha is a means of poverty alleviation, but the money seldom solely serves the needs of the intended recipient (Lund, 2006). Not every mental health condition qualifies for a disability grant. Poor households have no health insurance or financial reserves to fall back on when they have to care for a seriously ill family member.

55 Occupational therapists as service providers in the social field focus on occupational enablement, empowerment and enrichment (Wilcock, 2006; Galheigo, 2005; Kronenberg et.al. 2005).

survival[56]. To reduce disability in ways that could lead to the loss of social security would potentially compromise the financial status of the household. According to Field (2003) poor households tend to rely more on exclusive social capital, that is, the assets and resources of close family and other kin. It is inward looking and binds people from similar sociological niches (for example clan lineage), reinforces homogeneity and is useful for "getting by". Inclusive social capital serves as a bridge to wider social networks. It links people to more distant acquaintances who move in different circles, generates broader social identities and wider reciprocity and is useful for "getting ahead"; climbing the social ladder as it were. The impasse created by the availability of a disability grant poses particular opportunities for addressing the poverty/disability cycle[57].

4.4.2 Impact of sociocultural form on occupational performance

Participants in the study inhabited three occupational worlds: the 'here and now' of daily doing; the 'there and then' of the informal relational economy (tribal and clan links with rural places of origin) and the 'beyond' in which activities and tasks were regulated by deferring to the living-dead. Occupying disparate yet dynamically related existential planes or realities, three lifeworlds as it were, meant that productivity was determined not only by what was produced or achieved in the 'here and now' but also by what brought meaning and purpose to relationships in the 'there and then' and the 'beyond'[58]. Time, especially how, with whom and why it is spent, may take on particularly nuanced meanings in certain African belief systems. Productivity, agency, time use, orientation to nature, human activity and interdependent relationships are organised according to metaphysical imperatives involving a hierarchy of 'beings' (Teffo and Roux, 1998; Mkhize 2004). The nature, direction and influence of action

56 Research conducted in developed countries indicates that individuals with mental illness often feel that they are unable to work, perceive themselves as unproductive and feel restricted in terms of choice of work and living (Boyer, Hachey & Mercier, 2000). This perceived restriction of choice may arise from the fear of losing government assistance and not making enough money to sustain themselves without this assistance (Laliberte-Rudman, et al., 2000). Alternatively, an individual with a mental illness may be "discouraged from engaging in normal adult roles" such as the worker role because there is a perception that the 'stress' of these roles may worsen symptoms of the mental illness (Mancini, Hardiman & Lawson, 2005, p. 51). The disabled person's engagement in work and their efforts to develop new skills and form relationships are viewed as risky because they are perceived as 'fragile' (*ibid*., 2005, p. 53). In this study poverty pressed disabled people to act, either in terms of their role as provider of a steady income or as contributors to a precarious subsistence through informal income generating occupations.

57 The adoption of a different ideological basis for rehabilitation has been put forward as one way to address this dilemma for example, community development through community based rehabilitation principles and practices (Kaplan, 1999; ILO, UNESCO, UNICEF, WHO, 2002).

58 Bevan (2004), in her analysis of assumptions about time and chronicity of poverty, points out that we all live in a 'moving now', but that people experience and respond differently to the passing of time depending on the biological, psychological and socio-cultural rhythms of their worldview. The pace of productivity in the 'moving now' in the African way of life may appear less driven or frenetic than the pace that is generally associated with modern lifestyles in the developed world.

and the motivation to be productive is determined by the amount of *isithunzi or sereti* (life force, energy, power) allotted to each object or organism within the circle of life. It is believed that things never happen by accident because created beings and objects are ontologically connected to one another, organised hierarchically and mutually influential (Teffo & Roux, 1998).

In the context of grinding poverty, the environment presses for productivity aimed at meeting immediate subsistence needs. Those are the tasks and activities that deserve attention in the 'here and now'. Tomorrow's financial concerns belong to tomorrow ... at most they may require saving for a decent funeral; one that will appease the *iziyanya* (ancestors); will provide for *ukubona* (for example, paying for relatives and friends to visit the family) or will cover the costs of visiting a diviner to obtain direction for the future. In between today and tomorrow life is lived teleologically (Mkhize, 2004); that is, actions and by inference occupations, are predestined to happen for a particular reason to someone at a particular locality and point in time. To 'do', 'be', 'know' and 'become' is to participate in the dynamic process of interaction between the parts (the individual occupational human) and the whole (the cosmic unity of the seen and unseen community). Occupation not only enables participation in daily life, it also happens metaphysically on another plane while facilitating acceptance and protection from shades during the living years and into the afterlife at death. Links between the three occupational worlds are mediated through maintaining 'there and then' connections and performing occupations with and for living relatives whenever possible. There was also another side to inhabiting three occupational worlds. Belief systems were closely linked to social control in the sub-text of participant's lives because the sublime goodwill of the ancestors and neighbours could not always be assumed (Yen and Wilbraham, 2003a). Financial and personal progress was constrained on occasion by fear of bewitchment and jealousy for example, one participant spoke about the isiXhosa proverb, "*the nail that sticks out must be hammered down*" in relation to her business. Niehaus (2001) suggests that the collective unconscious in poor communities is regulated by the 'fear of prosperity'. Power and politics, operating as forms of jealousy, may be couched in witchcraft discourses that attribute social inequalities to occult forces. This enables people to make sense of their deprivation and suffering and influences the choices they make about what and why they do

what they do everyday[59].

Esoteric beliefs and practices shaped the meaning and purpose of what people did everyday. According to Mkhize (2004, p. 35) the individual's *inkambo* (becoming) is determined by a 'life force' both internal and external to themselves that dictates what needs to be done and how the doing needs to unfold This stands in contrast to notions of 'doing', 'being' and 'becoming' described as subjective, individual self-realisation processes in the occupational science and occupational therapy literature (Wilcock, 2002;1998c). Distinctions between self care, work (productivity) and leisure that are used to describe occupational performance, while recognisable in form, only partially align with certain aspecs of African way of life[60]. Africans conforming to traditional belief systems tend to pay more attention to the sociocultural aspects of occupational form, that is, to relationships with ancestors (the living-dead) and others (the living) than they pay to themselves as actors engaged with occupations that can be categorised into hours spent at work, at leisure, caring for self or sleeping. For them necessary, committed, contracted and discretionary occupations are merged; their 'doing', 'being' and 'becoming' intricately shaped by the relational and subsistence economy of their lives.

4.5 CONCLUSION

This chapter described the direct financial and material and indirect socioeconomic costs to households associated with the needs and behaviours of mentally ill members. The strategies which people with psychiatric disability and their households used to navigate the daily struggle for survival were identified and discussed, highlighting the interface between the individual, the social and the structural. This was followed by a description of how extrinsic and intrinsic strategies for dealing with poverty and disability interacted with the basics of occupation. Confirming the inter-relatedness of necessary, committed, contracted and discretionary occupations for socioeconomic survival, the chapter argued that while poverty aggravates the precarious situation of mentally ill individuals and their households, they nevertheless mobilise financial, human and material resources for livelihood and

59 Ashforth (1998), commenting on witchcraft, violence and democracy in post-apartheid South Africa, suggests that poor people may seek to explain their continuing suffering by adjusting their explanatory frameworks. They have replaced oppressive racism with invisible and malevolent entities, creating a resurgence of superstition and fear of invisible forces to explain human misfortune. The intentions of invisible forces are made clear through dreams, omens, visions and warnings or through a change in fortune. Belief in these forces causes 'spiritual insecurity' which may restrict agency because people live in fear of displeasing the living and the living-dead.

60 There is no universal African way of life or African cosmology. As an essentialist phrase, it refers to indigenous ways of knowing and 'being-in-the-world' that takes into consideration the differences in worldview amongst different African people groups (Mkize, 2004).

participation in life through the everyday things that they do. In addition to the intrinsic purposes and meanings of everyday occupations, poor people also strategise in explicit and intrinsic ways throughout the performance of their various occupations to promote subsistence and survival. Major organising ideas centred on the structural barriers posed by underdeveloped public mental health services and the discursive social forces that shaped people's daily activities, tasks and roles. Using the primary income generating occupation of a psychiatrically disabled woman as point of reference, the next chapter serves as an exemplar of how the basics of occupation operated in the context of chronic poverty.

CHAPTER 5: INDIVIDUAL CASE STUDY: FINDINGS AND DISCUSSION

5.1 INTRODUCTION

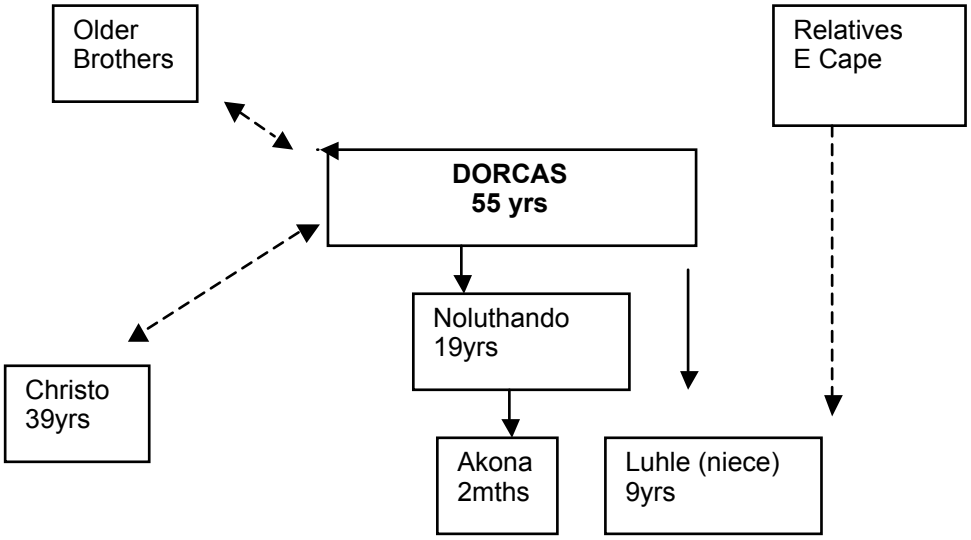
The last objective, addressed in this chapter, was to analyse the primary income generating occupation(s) of the disabled person with reference to the basics of that occupation namely: occupational form; the individual's developmental structure; meaning and purpose attributed to the occupation(s) and occupational performance (Nelson and Jepson-Thomas, 2003) . Due to length constraints, a detailed presentation of each individual case study is not included in this report . Following Stake (1994, p. 239), I selected Dorcas's case study as an "exemplar of the findings" because it best illustrated critical features about human occupation in the context of chronic poverty and psychiatric disability. It may be argued that the accuracy of the narrative, coming from a mentally ill person, may be questionable. Her biography was corroborated by her son, Christo and her friend, Modloko. Although Dorcas died of unknown causes during the latter part of the study, she did participate in the member check focus group that was held to confirm parts of the study findings. This chapter profiles Dorcas's occupational and health history in the context of her natal and current household structures at the time of the study and then describes her self identified primary income generating occupation of the selling second hand clothes using the basics of the occupation as conceptual frame. Combining recommendations by Stake (1995) and Creswell (1998) for documenting case study findings, the following format is used in presenting Dorcas's case study: background, personal history, categorical aggregation, major organising ideas and assertions (naturalistic generalisations). Discussion of the findings is interspersed throughout the case study which illustrates three points: some psychiatrically disabled individuals remain economically active in the informal sector through the strategic use of their disability grant as seed money for income generating enterprises; a stable and supportive informal relational economy (de Swardt, 2004) is critical for the sustained participation and productivity of psychiatrically disabled people and adaptive capacity, operating within the developmental structure of the individual and manifest in occupational performance, is an under-recognised form of agency. Cross case generalisation pertaining to the elements within the basics of the self selected income generating occupations of participants is presented in Appendix 9.

5.2 BACKGROUND: SOMNGESI HOUSEHOLD

The composition of the Somngesi household towards the end of the study period is depicted in Figure 6. The four-person Somngesi household consisted of Dorcas, aged 55, her 19 year old

daughter Noluthando, a nine year old relative girl child Luhle, and Noluthando's two month old baby boy, Akona. Dorcas's eldest son, Christo, aged 39, lived alone in another part of the township. He was disabled as a result of childhood poliomyelitis, walked with crutches and was also reportedly mentally ill…" *he has iinerves…". Christo locked himself up in his shack for days and refused to speak to anyone including Dorcas. She cooked for him on occasion because "he does not have a wife" and he sporadically contributed some of his disability grant (R50-R100) towards his mother's expenses. Noluthando, also mentally ill, refused to attend the mental health clinic and tended to be physically and verbally aggressive. "…I ended up calling the family to come and speak to her. She did not listen and they beat her. She left home when the family beat her…" It was unclear where she slept as she was "staying around" and "she is surviving by man (prostitution) …". Dorcas cared for her niece Luhle on behalf of relatives and little Akona because Noluthando was unwell "… this is her (Noluthando's) child and she is receiving grant for her but she doesn't support the child (Akona). This child is supported by me and even her (Noluthando) is supported by me…". (Here Dorcas was speaking about Noluthando and Akona. In keeping with some English second language speakers, she used 'her' when referring 'him').*

Figure 6: Geneagram of Somngesi household (2004- 2006)



Dorcas's two older brothers lived in another township in Cape Town. She called on them as the need arose "….*I am under my brothers*…." [1]. Reportedly due to the regularity of her disability grant, Dorcas was able to reciprocate from time to time by housing and paying the school fees

1 See Chapter 3, point 3.3.12.1, page 90. Here Dorcas is referring to the traditional Xhosa arrangements whereby a sister falls under the patriarchal authority of her elder brothers if her father has died and she does not have a husband.

for one of their children[2]. Luhle is featured in this report because she stayed for the duration of the study. She was placed with Dorcas to assist her in the home and to look after Akona. In return Dorcas paid for her education *"... I was given this child (Luhle) by my family since I cannot wash my clothes so she is doing my washing, looking after the baby and I am educating her..."* .

Dorcas' dwelling was situated in an alley amongst a densely built cluster of shacks, each built sequentially onto or adjacent to each other. The Somngesi's reportedly lived for 18 years in the same small, three partitioned informal dwelling built on bare sand with corrugated iron sheeting and cardboard. Besides a small window that could not open, the front door was the only ventilation and source of natural light. They shared a three quarter bed, used a paraffin stove for cooking, candles for lighting and had very few assets besides a broken fridge, a few cooking utensils, a small dresser and a well-worn, two seater couch. They made use of a communal tap and one of three flush toilets within walking distance of their dwelling. One of these toilets was broken, the second was very dirty and the third was padlocked and kept in a reasonable condition by a group of users who shared the key. This ablution set up was practice throughout the township and Dorcas reported that *"...we pay R2 or R5 for using toilets..."*. *"...at times you cannot use bed pans as people working for the municipality complain... "*.The dwelling was wired (illegally) for electricity which meant that they had access to energy when they could afford it. The fridge was used to store ice lollies and other perishable food which Dorcas sold from her dwelling before it broke down some time before the study commenced. She stopped using the fridge because neighbours complained that it made their electricity trip. It was never repaired due to lack of finance. The household subsisted on a meagre flow of cash into and out of the home obtained through a complex system of exchanges between a number of contributors and users (addressed later). One of the neighbours ran a busy spaza shop and was reportedly very supportive *"... even my neighbours do love me...sometimes I ask them to keep my grandchild and they look after him with pleasure..."*.

5.3. PERSONAL HISTORY: DORCAS SOMNGESI

Table 10 captures critical junctions in Dorcas's personal history. It summarises reported focal occupations and events at each age and stage of her life that led to turnings in her occupational performance.

2 During the period of the study, Dorcas looked after a two different children besides Luhle and little Akona. Each child only stayed for a few months.

Table 10: Timeline of Dorcas's life turnings

REPORTED FOCAL OCCUPATIONS	Trade/barter vegetables, clothes, wood, livestock (poultry) Fetch water, collect fuel, hoe fields, wash clothes, watch livestock, look after younger children, attend school (grade 7)			Makoti duties: homestead maintenance, fetch water, collect fuel, prepare food, hoe fields, do washing, child care		Severe poverty, very little to do all day, no job as too ill, severe hunger, looked after by elder brother, no financial support from father of her child, gets job as a domestic worker		Starts trading sweets and suckers, business unprofitable, (too much competition), changes to 2nd hand clothes in early 1990's.	
LIFE EVENT	Mt Frere Rural agrarian	Father dies, sent to relatives,.	First child, disabled by polio	Marries shepherd 3 children die in infancy	First illness episode	Divorced Moves to Cape Town 2nd episode	2nd child 1987, Gets DG, secures own shack	3 episodes & 2 hospital admission,	Dies, unknown cause
TIME LINE	Born 1951. youngest of 5	Age 12	Age 16	Age 20	Age 28	Age 33	Age 35	Age 37-55	Age 56

(Makoti: young woman/bride)

Dorcas reported that she was born and raised near Mount Frere in the rural Eastern Cape during the 1950's. Like so many other households heads at that time, her father worked on the mines in Johannesburg and sent remittances home whenever he could. Her mother contributed to the family income by selling indigenous medicinal plants foraged in the bush surrounding the village where they lived. The youngest of five children, Dorcas learnt from an early age how to tend the soil, plant and harvest maize and vegetables, mind livestock, raise poultry, crochet scarves, knit jerseys and run a homestead. Each family member was allotted chores and everyone contributed to the livelihood of the household irrespective of age.

"*... we were planting seeds and each and every child had his own plot. We used to wake up in the morning and irrigate our plants, after that clean the house then prepare the meal. After we have done all that we used to do our parent's washing and go to the bush to look for wood. Then we irrigate the plants again in the evening ...*". Girl children crocheted wool products which they sold at a local trading store. "*... we were crocheting wool bedspreads, mats, socks and children's hats and wool overalls to sell ... so that's what me and my sister did to help the family in poorness ...*". Boy children herded livestock and tended the land. One brother bought newly hatched chickens in bulk and each member of the family raised an allotted number of chickens for sale, in the process learning to budget, plan, solve business problems and save enough profit to buy the next batch. "*...we used to divide the chickens so each person had a few themselves. Then after three months we would sell them so that we can have money*". *Dorcas's older brother, at this stage working at a dairy near Cape Town, sent home second hand clothes for his sisters to sell. Dorcas learnt how to trade clothes, a skill that would prove to be very useful later in her life when she moved to the city. "...people who came from Cape Town*

used to bring along the second hand clothes and we barter with them. We use to take woods to those people and get second hand clothes in return which we then sold …" .

After her father's death, when Dorcas was 12 years old, her mother distributed the five siblings amongst the extended family. "… my mother divided us and put us on other homes for work. I was put on the location called … I went there to study and baby-sit my cousin's baby. Those people educated me …". Dorcas, raised by an aunt, completed Grade 7 at a Catholic school. In return for accommodation, each child was expected to contribute something towards the livelihood of the household where s/he was placed *"… we used to plough maize and cultivate that where we lived … we had bags of maize and beans to sell to get money so our brothers could get circumcised …" . In 1966 Dorcas married a shepherd with very few assets. She reported that the marriage was unhappy due to a clash of beliefs. "… I was under that family and I was very unhappy …".*

Dorcas had her first psychotic breakdown in 1979 as a result, she believed, of bewitchment. *"… I was bewitched. My man wanted to get rich and got himself a big snake from a witchdoctor that he believed would bring him wealth. I was not supposed to see that snake and when I saw it I became ill. I was shocked by the snake he received from the witchdoctor. The spirit of the snake shocked me purely because I did not agree with what my husband was doing and we fought about it daily …"*[3] . Dorcas set fire to huts causing significant loss of assets *"…I burnt all my clothes and my brother's together with my sister's… then they did not have any clothing and suffered… ".* She was bound up and locked away for two days until her family sent an ambulance to take her to a psychiatric hospital where she stayed for an indefinite period of time (unable to recall). Dorcas subsequently divorced her husband and moved to Cape Town in search of health care and employment. Her early years in Cape Town were characterised by severe poverty and hunger because she had no income and was reliant on the care of her elder brother. *"… I was very poor, not receiving a grant, living with my brother…. I used to be very hungry, struggling to get something to eat…."*

Dorcas had a number of admissions to psychiatric hospitals in Cape Town for psychotic behaviour, such as running around naked in public and becoming generally unruly and irrational. *" … (friend speaking) … you know when she is ill it is not a good sight, she takes off*

3 Mamlambo (a spirit familiar in the form of a river snake) is considered very potent. It is capable of multiple metamorphosis, including masquerading as a woman who seduces men. Illness caused by seeing the river snake is always considered to be more severe than other forms of bewitchment and may even lead to death unless the person is protected by the shades (Field notes, conversation with D. Bub, OT and trained sangoma, April 2006).

her clothes and she runs outside. We must actually lock the doors when her things start …". She received monthly anti-psychotic medication which caused extra-pyramidal symptoms such as hand tremors, a drooling mouth and fatigue[4]. Dorcas had one close friend, her business partner Modloko, who looked after her. *"…I (Modloko) check up on her and find she is ill then I clean her house and sometimes even bathe her 'til she is better …"* . Dorcas acknowledged Modloko's support. *"… when the illness starts I pray that Modloko will come and lock me up here at home and give me my medication and I lie down so that I do not make a nuisance of myself …"* Compliant with medication she started to recover and was able to secure a job as a domestic worker during the early 1990's. She augmented her income with informal trade of chips, iced lollies and other packaged foods from her home. She eventually stopped working due to her poor mental health *"… I stopped because I was 'ukugula ngengqondo' (psychotic)..* " and subsequently decided to start selling second hand clothes to augment her disability grant. During the following years Dorcas adapted her occupational performance according to her fluctuating mental and physical health, ran her home and managed her business all the while tolerating public abuse. *"… even when I go to the tap to get water the children make fun of me calling me 'rakie' (mad person)… ". "… (Modloko speaking) people tease Dorcas in many terrible ways … when she is sitting there they do not take her seriously … they still think that her selling clothes is part of her illness and not just a business like everyone else's …".* Dorcas regularly attended the Universal Church[5] where she found spiritual support for dealing with the emotional challenges of her life *"…the Universal Church give me holy water, bandage which they say I must use it when I feel sad or frustrates I must put it anywhere or in my heart if I am frustrated if I feel a headache in my forehead….".* Dorcas died from unknown causes in April 2006[6].

5.4 CATEGORICAL AGGREGATION

The following section describes and discusses the findings that emerged from deductive axial coding, interpretation and thematic analysis of data pertaining to Dorcas's primary (self identified) income generating occupation of selling second hand clothes. The conceptual

4 As a cost saving initiative, public mental health clinics are supplied with a limited range of psychotropic medication. The side effects of the medication (tremors, drooling mouth, muscle rigidity) may be as debilitating as the mental disorder itself.

5 The Universal Church follows a syncretistic belief system including elements of Christianity, esoteric mysticism, the paranormal, alchemy and belief in other beings called 'spirits of nature'. It revolves around messages received from ascended masters. Members practice prayers, affirmations and mantras with the purpose of devotion, calling the angels for protection and God's light to the world for healing and wisdom. Available: http://en.wikipedia.org/wiki/Church_Universal_and_Triumphant. Accessed: 28 February, 2009.

6 Christo said she arrived at his dwelling late one afternoon complaining of a sore stomach. She went to sleep and died during the night. He was unable to report on the autopsy result saying he could not recall that it was ever done.

framework for the basics of occupation (Nelson and Jepson-Thomas, 2003, p.91) provided a structure for categorical aggregation of codes[7]. Findings and discussion of each basic component of the occupation of selling second hand clothes follows. Table 11 depicts findings associated with occupational form as it impacted on Dorcas's performance. As a component of occupational form, Table 12 depicts the Somngesi household estimated monthly income and expenses over one month in the early part of the study. Table 13 addresses her developmental structure and the role it played in facilitating or hindering her functioning and participation as a person with a mental illness. Table 14 covers the meaning and purpose she attributed to her primary income generating occupation and Table 15 concludes with an integrated description of her overall occupational performance in productive, self care and leisure pursuits in relation to the contracted occupation of selling second hand clothes.

7 The units of analyses were pre-determined by the selected conceptual framework of the basics of an occupation: see Chapter 2, point 2.2.2 and Chapter 3, point 3.3.3. Nelson and Jepson-Thomas (2003) propose that occupational form consists of physical, material and sociocultural dimensions; developmental structure involves sensorimotor, neurophysiological, cognitive, affective, conative and psychosocial functions (performance components) as well as role performance; meaning and purpose may be understood by considering symbolic, perceptual and affective dimensions while occupational performance may be analyzed by considering 'doing' in the context of form. These pre-determined sub-categories for axial coding allowed the basic elements involved in the occupation of selling second hand clothes to emerge. The elements were then thematised based on interpretive analysis of all the codes in a particular category and its sub-categories. Elements in each sub category (right hand column of each table) were identified by interpreting the meaning of individual codes.

Table 11: Occupational Form (OF): prevailing influences on Dorcas's performance of the occupation of selling second hand clothes

THEME Core feature of OF	THEMATIC DESCRIPTOR What was Dorcas's unified response to OF?	THEMATIC CATEGORIES How was OF structured to elicit relatively predictable OP?	THEMATIC SUB-CATEGORIES What categories of OF existed in the data?	ELEMENTS IN THEMATIC SUB-CATEGORIES What elements of OF impacted on OP? [1]:
" Poverty is in the order of the day and there is scarcity"	"...the community supports me to survive by life..." "...some people can be very cruel..."	A CIRCUIT of SUPPORTIVE AND UNDERMINING SOCIAL CONNECTIONS	Supportive social interactions Undermining social interactions	ACTORS immediate & extended h/h members, 'homeys[2]' neighbours, business partner, spaza shop[3] owners, 'vambos'[4], traders, wholesalers, loan sharks, burial society, church friends, clinic sisters
	"...sorting things out with the DG..." "...they take advantage that I am a mentally ill person..."	A WEB of GIVING AND RECEIVING TRANSACTIONS	Exchanges outwards: expenditure & goodwill or malevolence towards others Exchanges inwards: income & goodwill or malevolence from others	RULES: payment in cash or kind (clothes, fuel, food, help); loan in cash or kind; fee for service; ascribe intentions
	" ...finding a good way to do business..." "... if I had better housing my life would be better..."	INFORMED TOPOGRAPHICAL ORIENTATION	Physical/environmental facilitators Physical/environmental barriers	TOPOGRAPHY: Micro environment: inside dwelling (storage space, security, fuel/energy); access to communal tap, toilets, Meso environment: transport routes (best places to hitch, rest, shortest distance to walk), where current cheapest wholesalers/ bargains are; market place (time/day/ where to sell eg. best pavements/ spaces/ places/ volume of human traffic); where debtors/ creditors live
	"... I was raised like that ...." "... those snakes (witchcraft) are dangerous..."	A TRADITIONAL (Xhosa) FRAME of REFERENCE	Sociocultural signifiers Sociocultural restraints	SOCIAL CONVENTIONS ito authority; social roles, life events, productivity; self/other people; health, well- being & illness behaviour
	".... the clinic is very good...." "... there are always fires that destroy our things...." "... people do not have any money out there..."	A COLLOQUIAL READING of CONTEXT	Systemic/structural enablers Systemic/structural constraints	CIVIC STRUCTURES staying informed about local social and civic affairs, accessing health care; social security, police, education etc. having political awareness and knowing what is happening ito socio-economic events in society (eg interest rate hikes)
	".... the DG cannot sustain us until the end of the month..." "...there is absolutely nothing to eat...." "... when you are poor and you ask for one thing and people are unable to give, they will offer you something else...."	A PRECARIOUS SUBSISTENCE	Material resources obtained or exchanged Non material resources obtained or exchanged	MATERIAL RESOURCES: money, clothes, food, goods, fuel NON MATERIAL RESOURCES: advice, information, protection, help, labour, emotional support

Table 11: Explanation:

1. Each of these elements featured in individual codes. Interpretations of meaning were deductively sub-categorized and then categorized using the features of the basics of occupation. The core feature of the prevailing influences on Dorcas's performance of the occupation of selling second hand clothes is thematically described using her own words. These codes were deductively selected as best representing the essence of the data. The same deductive approach to data analysis and interpretation was used in each of the categorical aggregation Tables 11,13,14,15.
2. "Homey" is someone from the same geographical area and tribal connections in the Eastern Cape
3. "Spaza shop" is an informal trading post
4. "Vambo" is a foreign national (usually from Namibia)

5.4. 1. Findings: occupational form

Table 11 captures elements of occupational form associated with the occupation of selling second hand clothes. Dorcas's occupational performance occurred within a **circuit of supportive and undermining social connections** between a familiar set of actors who were part of the occupational form within which she operated. These connections consisted of affirming (supportive and helpful) and undermining (alienating and unsupportive) relationships. The reported actors were immediate and extended household members including her two brothers who, though unemployed, were able to support her financially from time to time; "*....its our brothers who advise... they are not working also but they support me by giving me money or buy things for me...*" ; a 'homey' who stored her goods in his shop so she did not have to carry the bags of clothes every day between her dwelling and the pavement where she traded "*... I store my stock with the Rasta, he is my homey ...*" ; close neighbours who looked after her dwelling and grandchild when needed "*...even my neighbours do love me. Even when I go I leave a message to them and if I have visitors I also tell them. Some times I ask them to keep my grandchild and they look after him with pleasure...*"; a business partner (Modloko) who facilitated her participation in practical ways "*... I help Dorcas with carrying the stuff and monitor her so that she does not get tired quickly...*" ; specific spaza shop owners who were willing to extend credit on the basis of her regular disability grant "*...Rasta gives me on credit and I pay him when my disability grant comes. He just notes them in the book...*" ; wholesalers who created a trading infrastructure of 'bargains' and 'discounts' "*...buy it at low price and get discounts at that shop as regular customers. In December we also receive presents from that shop...*"; specific loan sharks who she believed exploited her but without whom she could not meet her financial obligations at critical times "*...sometimes you borrow R50 and at the end of the week or month you end up owing R600...*" ; burial society and church members who created a social support network "*...I take the rest of the money to the funeral policy that I have joined...*"; clinic sisters who knew her well and were willing to give her medication even if she did not bring her clinic card along..." *sometimes I even forget my clinic card but they give me my injection so I can go and sell my second hands...*" ; and the general public (business patrons) whom she felt both supported and abused her because she was mentally ill.; "*... some*

can be very cruel to mentally ill people like me… they try to fit some clothes on and tell you it's too small, but they continue until the clothes tear and then leave them so I cannot sell them…".

Each actor played a particular role in a **web of giving and receiving transactions** with Dorcas that were subject to tacit rules of engagement involving payment in cash or kind (clothes, fuel, food, help); loan in cash or kind or fee for service. " *…we buy there at the Coloureds in Mitchells Plain at low prices and we get discounts at that wholesalers shop as regular customers…". "… I take it to the Vambo's who are usually carrying clothes and I exchange with cutlery and ornament for clothes..". "…(friend speaking)she cannot handle it (washing clothes) so she hires someone to do it for her at the charging rates of R10-R20 which she would normally pay once she gets the grant…".* The rules of engagement were also subject to sociocultural signifiers and restraints within a traditional (Xhosa) frame of reference. Social conventions informed reactions to and conceptions of authority; social roles, life events, productivity; self/other; health, illness and illness behaviour were mediated through a cultural lens. *"…I liked the way my mother did and I wished that I could raise my children like she did us….". "…my family-in-law is very much into ancestors and rituals and witchdoctors and all and in my maiden family, the way I was raised up, that is not accepted…" "….my family-in-law do not want to see me today because they believe that my illness is a cultural health issue and not a health medical issue….".* The web of transactions enabled the Somnegesi household to maintain a precarious subsistence by accessing a range of material & non material resources. The type of resources and the many exchanges within which they were embedded becomes clearer by looking at an estimate of the Somngesi household income and expenses captured in Table 12. It depicts the household's cash flow based on reported income and expenses during an average month in 2004-5. Dorcas said the exact amount of cash flowing in and out of the household was difficult to record because *"….I don't write down, I keep on mind because I can't write my hands are shaking…".*

Table 12: Somngesi household estimated monthly income and expenses[8]

INCOME		EXPENSES		COMMENT
From	**Approx. amt**	**Approx. amt**	**Paid to or for**	
Disability grant	R780 (2004/5)	R37 x 4 = R148	Burial society	She sometimes paid 3 months in advance
Sporadic remittances from: Christo's DG, Child Support Grant (when she was looking after a child), Noluthando's prostitution	R50 to R100 (CSG: R180) R50-R100	R65 to R110	Crèche and /or school fees	Depended on age of child
2nd hand clothes sales	Approx R75-R90 per week =R300-R360	Approx R100	Buy Tupperware, ornaments, cutlery to barter for 2nd hand clothes	Built relationship with wholesaler and 'Vambos' to get products at discount
Loans from: brothers, friends, (avoided loan sharks but used them from time to time) Credit at spaza shops & wholesalers	Ran as high as R600 some months; seldom below R500	Depended on amount loaned from & to people	Loan & credit repayments PLUS extending loans to relatives & friends. Complex system of loans & credits existed.	Creditworthiness confirmed by being recipient of a DG. Relatives extended interest free loans. Loan sharks charged high interest rates. Amounts exchanged varied
	Dorcas estimated cash into the h/h: R1180	Dorcas estimated cash spent by the h/h: R1000	Fuel, Food Transport Toilet, 'Pocket money' for clinic visits Fee for service	Paraffin (20 litres) & candles R60-R100 for electricity Bulk buy 1x mth; R110 for bulk buy staple food to be shared between h/h's; R10 for petrol to person doing the bulk buying; R2-R5 for toilet use along the way during stocking trips; R5-R10 for someone to go to clinic with her plus food; +/- R20 for assistance with committed and necessary occupations e.g. washing clothes

Table 12 provides an incomplete but informative picture of the tenuous financial situation in the Somngesi household. Although reportedly insufficient, the disability grant anchored the livelihood of the Somngesi household by providing a regular income and providing seed money for the augmentative income business of selling second hand clothes. It was also augmented by loans from relatives or friends; credit from spaza shop owners; contributions from Christo (the amount fluctuated depending on his mood) "*…. he sometimes gives me R50 or R100…*"; the child support grant and sporadic contributions from Noluthando which she earned through prostitution "*….she is surviving by asking money from men and by sleeping with these men and then give her the money…*". While the disability grant provided a regular income, Dorcas said that it was insufficient to meet the needs of the household. "*…the grant cannot sustain us until the end (of the month)….I pay the funeral scheme, buy food, clothe the children, give them pocket money for school; it really gets finished before the end of the month….*" She reported that the grant was a source of stress for her "*…by the time you go for*

8 Information in Table 12 is based on interview data. The table was collated by identifying single codes containing information about the flow of cash or kind into and out of the household during one month in the first year of the study (2004/2005).

collection you have already budgeted your debts but when you put your finger they tell you that your grant cannot be processed but rather go for renewal. Imagine those debts, which is what causes us to be frustrated…..”[9]

The precariousness of her financial situation was offset by having relatives who lent her money interest free. *“… there is a shop owned by relatives where I usually borrow some money and buy food on credit instead of going to the loan sharks….”; “…most households go to loan sharks to fulfil immediate needs like contribution to [burial] society..”.* She augmented the grant by selling second hand clothes. *“… if I don’t sell clothes and just depend on the grant I am unable to make enough groceries. The grant money only allows me to buy 5kg packets but I actually prefer 10 kg or 12.5 kg [of meal] because they last us so that is why I continue with this business. 5 kg do not last us and it would mean that I have to go to the shop and take on credit. By the time I get my grant I cannot use it for anything that we need here at home because I have to pay the debt that I would have made at the shop….”.* Dorcas also loaned money to people or extended them credit on payments for garments. She reported losing money from non-settlement of these debts. *“… in the end its difficult for them to repay so much so that in 2001 I got beaten up by this other lady who took clothes on credit and I was hospitalised…” ; “…they become cheeky with my money… sometimes they wear it and wear it and when I go collect my money, I see them bringing it back with no explanation…. ” ; “…some other people take something on credit and say she is coming back now and that will be the end of it, that also frustrates me, or they make a shortage, not paying back in full…”.* While non-material resources in the form of advice, information, protection, help, labour and emotional support eased the burden that Dorcas felt she carried, she was concerned about the lack of involvement by her children in the running of the home *“… it is good that Modloko [friend and business partner] helps me because our children today do not even think about helping us in the things we do for them….”. “ …not only do I (Modloko) help her with her business but sometimes also with her household chores. Sometimes I come to check up on her and I find that she is ill and there is absolutely nothing to eat. I tell her to lie down a bit and I will clean her house for her and go alone to the street corner and make some money for her so that she can have something to give to the children…” .*

9 The South African Social Security Agency (SASSA) has stipulated criteria and processes by which social grants are issued including a means test. Temporary disability grants are issued based on the type of psychiatric diagnosis; duration of condition and prognosis. Here Dorcas refers to an occasion when she was informed that her grant period had expired.

The efficiency of Dorcas's occupational performance was supported by the use of a well **informed topographical orientation**. This involved topographical knowledge about the micro (inside her dwelling when she became confused or struggled with her memory) "*... I can't even forget did I put my money or anything else I want to place so I call the little child (Luhle) to look where I put something so that when I want it she will remind me of that place...*" and meso environments in which she functioned (eg.in the surrounding neighbourhood). The spatial orientation kept Dorcas informed about performance facilitators and barriers in the meso environment including transport routes (best places to hitch, rest, shortest distance to walk), wholesalers (current cheapest bargains available); market place (best time/day to obtain and sell second hand clothes including best pavements/ spaces/ places/ volume of human traffic) and where people lived so she could cold call to collect money that was owed to her. "*..we go around looking for the cheapest stores so that we know where each item is... we buy bulks like maize meal, sugar, sunflower oil... we sometimes buy that item together by putting money together and later split the food equally amongst ourselves...*"; "*...we put aside about half of our profit for bartering, the rest we use for fuel and food ... like if we get R30, we will put away about R12 for more Tuppers ...*"; "*...we walk anyway (28 kilometers) and we stop for a while at the last four-way stop out of Khayelitsha and we stand there for a while and try hitchhiking.....*" ; "*..sometimes others help us when we hitchhike to an extent they take us back and forth...*".

A colloquial reading of the systemic/structural enablers and constraints in her immediate **context** helped her make sense of civilian issues; identify the best market opportunities and access public services as she needed them. "... we used to sell in Site C at the taxi rank but more and more taxis are joining the rank and it became too full around the spot where we were stationed ... there was too much competition ... now we are just selling here on this street corner ..." ; "... we were looking for a place where lot of people pass ...". She recognised the principles of business in relation to the general state of the economy, including how the rise in unemployment impacted on the profitability of her enterprise. "*... when I started I would go to Kraaifontein waking up at 4 am. When I get there I sit and wait for the trucks that are selling clothes, when we were still buying clothes. We do not buy clothes now. We simply ask around for clothes by exchanging with cutlery, ornaments and Tupperware (plastic containers) here in Mitchell's Plain (a closer suburb) ... we buy the cutlery and Tupperwares at low prices at discount at a shop where we are regular customers. In December we get presents from that shop for being good customers ...*" ; "*... in previous years people used to buy a lot from me and my business was running smoothly but this year (2006) has been just another bad year ... people do not have money out there like in the past, they do not have jobs, so if few of them are working I will not see success in my business because I depend on them...*". She also

understood social dynamics "*...sometimes the ladies and youth come in (to her shack) because they were so embarrassed to buy from the street corner while everyone is watching so it's safe to buy from my home. They ask for address and directions to my place because they do not want people to know they are poor ...I take the clothes out for them and whosh... R50 comes in just like that!...*"

5.4.2 Discussion: occupational form

The unifying theme of the occupational form within which Dorcas functioned is captured in something that she said in one of the interviews: *'poverty is in the order of the day and there is scarcity'*. Form of occupation was experienced as limited, constrained and restricted ie. she had little (materially and physically) to work with and act on in a resource depleted environment. Dorcas navigated this form by establishing an intricate survival system within her localised lifeworld consisting of social connections, material and non-material transactions and particular ways of knowing and behaving, as the sub-categories in Table 11 indicate. Central to this occupational form was the fact that everyone in her social web was in the same boat; being poor was the way things were and everyone understood the implications of need and the strategies required to deal with scarcity. Poverty and scarcity did not, in Dorcas's case, pertain solely to the material, but also to the structural and social dimensions of form. De Swardt (2004a) speaks about an 'informal relational economy' in which kinship is only one of a complex range of social relations, affiliations, alliances and enmities that structure and are structured by informal exchanges of resources aimed at offsetting survival amongst the poor. Underpinning the relational economy are skills such as the ability to manipulate the urban system to gain access to services, juggle debts and obligations and managing risks by claiming membership of certain sub-groups for example 'stokvel' groups (informal savings schemes). Dorcas was very clear about whom she could trust, who she had to avoid and who was a pivotal link in the marketing making chain of her informal business.

Dorcas developed skills dealing with two sets of negative press: a structurally underdeveloped and a socially prejudiced environment. It was at this point that poverty, disability and occupation intersected in her life. She managed the considerable stigmatisation of her mental illness by developing an identity as a business owner and believing that her capacity to work hard was more important than the abuse that came her way. Without minimising the restricted circumstances of her life and the additional costs associated with her special needs, she was very often in a better position than many of the people in her circle of influence that did not have a regular income (Watson, 2005). The findings indicate that as a psychiatrically disabled person, Dorcas established a circumscribed survival infrastructure on

the basis of the bargaining power of her disability grant (MacGregor, 2006). While the grant elevated her economic status on the one hand, it potentially exposed her to exploitation on the other. The findings however do not indicate that this was the way she saw things, rather, she recognised the reciprocal pay off for the actors in her particular relational economy. The grant enabled her to remain occupationally engaged in her sphere of influence involving a range of actors for different purposes, some more benevolent than others. Her main concern was to keep the adjunctive income from the second hand business going despite the costs of stigmatisation and exploitation. This kind of dependency in poor communities is high. According to the Chronic Poverty Research Centre (2004), social capital in Cape Town urban areas during 2003-4 included church organisations (54%), funeral associations (58%), stokvel (credit scheme) (1%), groceries groups (7%) and community credit associations (3%). Despite this apparent social network, not everyone in poor communities have someone to turn to in times of need. Seekings, Alexander et al., (2003) found that 6% of people in urban Cape Town reported having no-one to turn to in times of need and 10% had received no gifts of food or money in the preceding month. Dorcas had people she could turn to; people she was able to engage because they relied on the spin off from her disability grant and she, in turn, could rely on them to help her manage her impairments. This dependency made her potentially vulnerable to economic exploitation (discussed later). Economic vulnerability, according to Du Toit (2004, p. 11) "feeds into - and its other impacts are often amplified by - the vulnerable, stressed, power-laden and conflictual nature of the social networks on which individuals and groups rely for identity, survival and dignity". Dorcas's economic vulnerability was offset by her reliance on Modloko and on the bargaining power that her grant made possible in securing the kind of assistance she needed to keep her business going.

Lund (2006), in discussing social security and gender in South Africa, points out that claims and counter-claims to goods and assets are mediated through different forms of social power operating within a particular network. While social capital[10] is often described in positive terms its contribution to poverty alleviation is in reality quite limited and ambiguous. Dorcas relied on and seemed to consciously manage a precarious supply of material and psychological goodwill doing the rounds in her network circle. The subtext of her communal foundation matrix[11] suggests that the social capital she relied on was not always benevolent.

10 Social capital refers to social networks and associations in which people participate, and from which they can derive support that contributes to their livelihoods (Ellis, 2000a, p.8). Shifting social dynamics mean that this form of capital is not consistently benevolent and accessible as Dorcas suggests in relation to Modloko and her neighbours.

11 See footnote 28 for definition and discussion

Yen and Wilbraham (2003a,b), describing the pathogenic constructions of envy and jealousy amongst the poor, suggest that the 'good things' that are assumed to exist in impoverished communities are, in reality, shaped by complex social norms, meaning-making practices and ideologies that determine how resources are distributed. Conflict and jealousy was rife in the sub-text of Dorcas's narrative. Yen and Wilbraham (ibid, 2003a,b) point out that under these conditions a favour secured is also a debt owed, adding to the difficulties individuals have in accumulating savings or investments that can lead to an escape from poverty.

Table 12 portrays, albeit incompletely, just how close to the edge Dorcas had to balance the flow of resources into and out of the household. With every balancing act, came a fragile relationship that had to be managed. There was no way in which she was able to accumulate any savings or make any investments to escape poverty, her investments were phenomenologically situated in the immediacy of daily survival, maintaining or establishing day to day relationships and the 'here and now' exchange of goods needed for survival in the short term. The Somngesi's were a vulnerable household as she herself noted *"…when I become ill nobody will be working until I become better again…"*. According to Wood (2003), poor people often opt for the slippery slide of dependency in exchange for security, choosing 'risk management in the present' over investment in the future. In her desperation to survive, Dorcas incurred debt in the 'here and now' to secure food and resources to meet basic needs even when this resulted, in the long term, in dependency on individuals who appeared to be exploitative as her comments on Modloko suggest. Paradoxically, Dorcas's adaptive capacity[12] was brought to the fore by Modloko. Without this friendship, she would have been unable to deal with the challenges of psychiatric disability. Assumed 'neighbourliness' was built on obligations that Dorcas incurred by borrowing money and receiving assistance that enabled her to function as a disabled person. Obligations carried with them threats to her major asset, the disability grant yet these obligations were intricately connected to maintaining her occupational performance in an income generating occupation. She was aware of the contradiction stating that *"…they take advantage of me that I am a mentally ill person…"* and she questioned Modloko's motives for being so helpful *"….she is a thief, her children are thieves… she is getting lazy now and is going deeper into stealing [Dorcas intimated here that she was wary of Modloko's honesty in regards to their business profits] and I am beware of her now…."*[13].

12 For definition see footnote 18

13 It could be argued that Dorcas's opinion of Modloko may have been paranoia, a feature of certain psychiatric disorders. There was no indication, based on regular brief mental state assessments by the two researchers, that she was clinically paranoid.

The uptake of grants nationally is a means of poverty alleviation, but the money seldom solely serves the needs of the intended recipient as Dorcas's case study indicates (Lund, 2006; MacGregor, 2002, 2006). According to MacGregor (2002), grant recipients are in an invidious position whichever way they turn; they are dependent on the household which in turn is dependent on them. She states "*given the difficulties associated with generating an income, the disability grant represented a very powerful tool to improve the well-being of persons with [mental] disturbance*" (*ibid,* 2002, p.84). Dorcas operated in a narrow and relatively stable circle of relational economy in which most of the primary actors, in particular her best friend and business partner Modloko, knew that she was vulnerable by virtue of her mental health history. They accommodated her impairments thereby creating opportunities for her to sustain productivity. What was in it for them? What underpinned the (in)stability of her social capital? The findings suggest that Dorcas used her disability grant in strategic ways that took into account the balance of power within her social network, determining each person's contribution either in relation to her business or in terms of their contribution to the household's financial and interpersonal functioning. As the holder of the grant she had particular rights and social value which she used to determine what other actors in the circle got out of being associated with her. Different people got different gains for example, Luhle's[14] parents got their child's education paid for while Dorcas gained someone to assist in the home[15]. Irrespective of the type of gain, socioeconomic co-dependency seemed to act as the cohesive and corrosive element within Dorcas's occupational form.

Beall (1995, p. 35) suggests that "*... from a policy perspective, it is important to remain clear that reciprocal relations among the very poorest are particularly fragile and provide an unstable base for long-term security. For social networks to constitute viable and sustainable survival strategies, people require at least a minimum degree of economic stability, social respect and organizational capacity*". This is particularly pertinent for disabled people. It is unclear why three members of this household suffered from a mental illness and it would

14 The possible emotional impact on Luhle of being separated from her parents and siblings, moving to the city from the rural area and being exposed to the mental instability of her urban relatives raises questions about the intergenerational transfer of human poverties and the need for policy attention to the psychosocial functioning of households affected by psychiatric disability and chronic poverty.

15 The intergenerational transmission of unmet human needs from 'parent' to 'child' occurs within the living spaces that they both occupy (Moore, 2001). Factors that are transmitted include financial, material and environmental capital such as cash, debt, land, livestock; productive and non-productive goods such as ploughs or television; human capital such as knowledge, skills and health or inherited impairments; social, cultural and political capital such as position in society; norms of entitlement, such as who is attributed what assets according to a 'pecking order' of power; intent and attitudes of the 'parent'; stigma and even a culture of poverty (Hulme & Shepherd, 2003b).

be speculative to suggest that there was a hereditary factor at play[16]. The point however is that the fragility of the relationships within the household compromised the stability of the relations beyond the household by virtue of the community's intolerance towards and prejudice against psychiatrically disabled people. Noluthando may have been vulnerable to exploitation by men due to her mental illness. Dorcas reported occasions of abuse which she associated directly with her status as a mentally ill person in the community *"... I think they did that to me because they were taking advantage of the fact that they know I was a mentally ill person and I was too old to do anything to protect myself..."*. The long term security of disabled people as active participants in the economy will require active advocacy about their rights and abilities. In addition it could be argued that a household such as the Somngesi's, representative of countless others who have a disabled member, would have benefited from assistance in achieving internal organisational capacity. In so doing, they may have been mobilised to access or to activate for mental health support and access to other public services. Dorcas stated that *"... I myself have never seen social workers in our area...."*. Receiving monthly psychotropic medication is not enough. People also need access to self help services that promote their dignity and development potential. Her request was *"... assist me to retain better health because when I am healthy, I would be more productive. If I would have better housing, my life would be better..."*. According to Narayan (2005, p. 3), poor people are trapped in poverty because they are barred from opportunity and therefore live their lives with little expectation that *"tomorrow will bring anything good except their arduous work"*. Although their freedom of choice to take action and shape their own lives is hampered by limited access to the resources and opportunities needed to maximise their assets and capabilities, a closer look at their developmental structure reveals a range of adaptive capacities. The categorical aggregation of the basics of Dorcas's occupation of selling second hand clothes continues in the next section. This time the focus is on the findings regarding the involvement of her developmental structure[17] in selling second hand clothes followed by a brief discussion of the findings in relation to the research aim.

16 Bipolar disorder occurs at a higher rate in first-degree relatives (Tsuang & Faraone, 2000).

17 Consider, for example, the impairment costs discussed in Chapter 4, point 4.2.1, page 100.

Table13: Developmental Structure (DS): performance component demands of selling second hand clothes

THEME Core feature of DS	THEMATIC DESCRIPTOR What was the unified organisation of the DS?	THEMATIC CATEGORIES What characteristics defined the DS?	THEMATIC SUB-CATEGORIES Which pertinent body systems/ structures were involved /affected?	ELEMENTS IN THEMATIC SUB-CATEGORIES Which abilities & skills were applied in relation to OF & OP?
"…. if I didn't get my injection, I get disturbed and don't do all these things…."	*"…within the reach of her strength and endurance…."* *"…this mother is tired and unable to do things for herself…."*	**A SCAFFOLD of ADAPTIVE STRATEGIES**	sensorimotor & neuro-physiological functions sensorimotor & neuro-physiological impairments	**ADAPTATIONS** **delegation**[1]: fee for service (eg. paid someone to do washing of clothes etc.) **relocation**[2]: eg. moved business to cut walking distance; changed suburbs for collecting clothes
	"…poverty makes you think & think…." *"…sometimes you are mentally affected due to deep thoughts that one engages due to money shortages and exhaustion of alternatives…"*	**A PREOCCUPATION WITH MONEY**	cognitive & affective functions cognitive & affective impairments	**diversification**[3]: identified numerous small ways to make or stretch money **compensation**[4]**:** got child to augment her failing short term memory & used faith strategies to deal with mood fluctuations
	"…my gift of making friends is from God…." *"… she avoids social settings and too many questions…."*	**A SELECTIVE INTERPERSONAL ORIENTATION**	psychosocial functions psychosocial impairments	**accommodation**[5]**:** reciprocity (business partners adjusted in relation to emerging needs) **isolation**[6]**:** withdrew, slept, locked self into dwelling when relapsed
	"….I am the principal breadwinner of this household…." *"…I (mother) raise them (children) with difficulty…."* *"…I see myself as a disturbed person…."*	**A BURDENED ROLE SCHEMA**[7]	role functions role challenges	**encapsulation**[8]**:** roles linked to survival were imperative –got on with life in spite of disability (impairments, activity limitations and participation restrictions) **modification**[9]**:** changed tasks & activities to match role demands and limitations imposed by impairments
	"…. I do all by myself…." *"…I just know I will succeed…."* *"…. I would just sit…."*	**A DETERMINED SELF POSITIONING**	motivational/ volitional functions motivational/volitional impairments	**anticipation**[10]**:** held a future orientated view of her life and responsibilities **valuation**[11]**:** operated from a foundation of values: autonomy, faith, trust, duty, responsibility

Table 13: Explanation:

1. Delegation: to entrust personal tasks to someone else to perform
2. Relocation: to reset position, to move to another place
3. Diversification: make use of several different options
4. Compensation: to make up for discrepancies or to counterbalance
5. Accommodation: to harmonize and make adjustments
6. Isolation: to become detached
7. Role schema: awareness of a social identity and related obligations. A role is a framework for appreciating situations and constructing culturally appropriate behavior (Forsyth and Kielhofner, 2003, p. 55).
8. Encapsulation: a psychological defense that works by enclosing (bracketing) a particular part of the self
9. Modification: to change the form or quality of something
10. Anticipation: deal with or be preoccupied with that which is still to come
11. Valuation: estimation of worth

5.4.3 Findings: developmental structure

Table 13 depicts the demands of selling second hand clothes on Dorcas's biopsychosocial developmental structure. Dorcas was not a healthy person *"… I couldn't cope with my mental illness and my body also gave in…"*. Having a long standing history of mental illness and numerous physical complaints did not however stop her from developing **a scaffold of adaptive strategies** to deal with the functional implications of various impairments. *"…we [friend speaking] monitor her so she does not get tired quickly …."*. *"…I am restless but if I am with someone I sit still…"*. *"..I [friend speaking] help her carry…heavy loads because her hands are constantly shaking especially when she is tired…"*. *"….I get injections but if I forget my date I will have a terrible headache…."*. *"… I can't even forget did I put my money or anything else I want to place so I call the little child (Luhle) to look where I put something so that when I want it she will remind me of that place…"*. Cognitive and affective functions and impairments associated with her health condition suggested periods of psychotic behaviour *"… I was mad, mad, mad…"*. A poor memory led to the loss of money on occasion *"…I am very forgetful, I forget and even lose my money, I lose all my grant payment…"*. **A preoccupation with money** reportedly dominated her thinking and feelings *"… sometimes you don't even sleep at night because you are thinking as there is no food… "… my heart becomes bitter… and sometimes I even cry.. " ; "….poverty brings back the pain…"*. There were indications that Dorcas was suspicious of other people from time to time and she therefore adopted **a selective interpersonal orientation**. She recognised when she was vulnerable for a relapse and would withdraw from social contact *"… sometimes I just feel like going into bed and sleep the whole day because I just cannot handle it (relating to people as part of the business)…"*. Dorcas had a **burdened role schema**. As a mother she was very worried about Noluthando not only because she was mentally ill, abusive and "sleeping around" but also because she was *"…neglecting her child…"* and not fulfilling her cultural role expectations *"…I did not raise her like that…"*. Dorcas was proud of her abilities as a business woman yet found the role functions and challenges burdensome in view of the relentless demands on her to provide for the household *"..I am the principal breadwinner of this household…. ". "…I am responsible to provide…"*. She articulated a **determined self -positioning** in which she recognised that while her motivation fluctuated from time to time because she felt tired and overwhelmed, she nevertheless applied drive to achieve her goal of being a provider and role model. *".. I lie down so that I do not make a nuisance of myself…". "… I stopped (selling sweets etc) because I could not cope anymore.." ; "..I've been trying and trying to succeed…I am trying the best for my children to leave them with something that they can live with and to teach them how to survive in life as I was…"*. Dorcas was very clear about who she was and how she wanted to be *"… I do not like to be dependent when I am still alive, I like*

to stand in my own with my children... "."... I can even do better than those who are working."

Dorcas, with the assistance of Modloko, made various adaptations to the way she went about her daily activities and tasks in order to accommodate her functional limitations. These included *delegation* (eg. paid someone to do washing, ironing etc of second hand clothes), *relocation* (eg. moved business to cut walking distance), *diversification* (eg. identified numerous small ways to make or to stretch money), *substitution* (eg. got child to augment her failing short term memory and used faith strategies to deal with mood fluctuations), *accommodation* (eg. business partner adjusted tasks in relation to emerging needs), *isolation* (eg. withdrew, locked into dwelling when relapsed), *encapsulation* (eg. bracketed disability experience; necessity overrode illness as well as her response to prejudice - she simply ignored what people said and got on with her life), *modification* (eg. changed tasks to enable functioning for example changing walking routes to make them shorter and using walking stick), *anticipation* (eg. held a future orientated view on her life and responsibilities) and *valuation* (eg. operated from a foundation of values: autonomy, faith, trust, duty, responsibility). In short, Dorcas's developmental structure suggested a person living under considerable strain who, despite a number of debilitating impairments, was able to overcome activity limitations and participation restrictions through adaptive capacity[18]. This feature of human occupation in the context of chronic poverty and psychiatric disability is discussed later under points 5.6 and 5.7.

5.4.4 Discussion: developmental structure

The unifying theme of Dorcas's developmental structure was, in her own words, indicative of her vulnerability as a result of her health condition and her reliance on medical intervention to maintain her functioning **".. if I didn't get my injection, I get disturbed and don't do all these things.."**. Her developmental structure, as a basic element of the occupation of selling second hand clothes, operated best when it was enabled, mediated, regulated ie. it required external intervention to function optimally. Central to this theme is evidence that good mental health care, medication and psychosocial support (as was offered by Modloko)

18 Adaptive capacity is the capability an individual possesses to perceive the need for change, modification, or refinement (adaptation) of an occupational response in order to respond with relative mastery (Schkade and Schultz, 2003, p.185). Relative mastery consists of three properties: efficiency (use of time, energy, resources); effectiveness (extent to which desired goal is reached) and satisfaction to self and society (extent to which person doing occupation finds it personally satisfying and the extent to which it is socially well regarded) (*ibid,* 2003, p.185). Given the extent of deprivation and marginalization experienced by Dorcas and other participants, their relative mastery was evident in the efficiency with which they were effective in meeting if not satisfying their basic needs.

go a long way towards ensuring that mentally ill people participate in their community and maintain a (reasonably) productive life. Both women also made use of the enabling opportunities provided with the occupational form to actively exercise greater control of their circumstances. Dorcas sometimes forgot to get her injection; on other occasions she avoided going to the clinic because, being restless, she could not face waiting in the long queues. She reported often leaving unattended because she was unable to tolerate the long queues. Without her medication, she was at risk of relapsing. To prevent this, someone would have to go with her who would have to forego a day's earnings or Dorcas had to pay him/her a service fee. In the context of grinding poverty, loss of a day's income, however meagre, can mean the difference between eating or not eating (Mitra, 2005). Her story suggests that financial considerations and long queues at primary health clinics may account for medication regime non-compliance; a problem associated with multiple relapses and readmissions to tertiary psychiatric hospitals. Relapses also have negative ramifications on people's adaptive functioning and ultimately reinforce the disability / poverty cycle (Yeo and Moore, 2003) operating in households with mentally ill members[19].

Patel and Kleinman (2003), writing about poverty and common mental disorders in developing countries, indicate that research confirms association between poor housing, overcrowding, feelings of job or income insecurity and the incidence of common mental disorders such as anxiety and depression. The experience of insecurity and hopelessness, rapid social change and the risks of violence and physical ill-health may explain the greater vulnerability of the poor to common mental problems. Based on an analysis of 60 published and unpublished narrative accounts of recovery from psychiatric disability, Jacobson and Greenley (2001) found that recovery from mental illness was attributed to personal factors such as subjective concepts of hope, adequate time for healing, empowerment and supportive social connection and environmental factors such as human rights, a culture of affirmation and recovery-orientated services. Having a job and stable routine also facilitates recovery (Crist, Davis and Coffin, 2000) as does managing and minimising the imposed identity of being a 'mental patient" or a "mad person" (Boyer, Hachey and Mercier, 2000). The findings indicate that Dorcas's occupational form impacted on her mental state. Some of her relapses were precipitated by factors in her lived environment. Johnson (2001) points out that, for some mentally ill people, the intensity of their mental and emotional impairments, concealed and experienced subjectively, is matched externally and simultaneously with stigmatisation. This is a perpetuation of "a most cruel injustice, notably, the denial of the mentally ill's

19 See Chapter 2, point 2.3.7, Figures 2 & 3

moral entitlement to things that other people take for granted: function, a sense of place in an intersubjective world, empathic connection with reciprocating others, peace of mind, happiness and participatory citizenship" (*ibid*, p. 200). Dorcas may have contributed to her own stigmatisation by having limited appreciation of the impact of her illness behaviour on others for example requiring restraint (being locked up to keep her from running around naked and beating on people) or by acting in 'odd' ways (she acknowledged that her behaviour, when ill, could be described as "mad". She nevertheless actively created restorative conditions for herself within the constraints of her occupational form and the 'narrowness' of her circle of influence. Despite experiencing frequent stigmatisation, she subsumed her illness identity into a reconstructed identity of self as business owner.

Possessing adaptive capacity did not however obscure the burden of her subjective experiences. Any appreciation of Dorcas as an occupational being must take into account what it must have cost her emotionally and physically to keep going in the face of enduring hardship. The suffering associated with mental illness is, as Johnstone (2001, p. 200) suggests, "incomprehensible to non-afflicted onlookers". We will never know the extent of her hardship. Access[20] to comprehensive (preventative, promotive, curative and rehabilitative) mental health services in townships such as Khayelitsha would have made a considerable difference to her recovery and the enhancement of her occupational strengths in the fight against poverty and disability[21]. She herself indicated that the only change she desired was to have a decent house and basic amenities. What kept her going? In the next section, the findings of the meaning and purpose[22] she gleaned from selling second hand clothes is presented and discussed[23].

20 Accessibility refers to the time, effort and cost, in brief the ease, with which a good, a service or a facility can be reached or used (Mitra, 2005, p.23).

21 The two largest health facilities in Khayelitsha are the Michael Mapongwana Clinic (MMC) in Khayelitsha town and the medical complex in Site B which is the only facility with a 24-hour casualty unit that also deals with psychiatric emergencies. There is a day unit at MMC. Slow ambulance response times are a huge problem, as people do not have ready access to private vehicles (City of Tygerberg Demographics, 1997). Queues at clinics are long and not everyone that arrives at a clinic can be attended to on that day due to staff shortages.

22 See Chapter 2, point 2.2.2, footnotes 15 & 16. To ascribe meaning to something is to give it significance either in terms of its symbolic, affective or perceptual value or in terms of its function or purpose in achieving certain outcomes or goals (Nelson and Jepsen-Thomas, 2003). These three dimensions of meaning were used as deductive sub-categories for meaning related codes. Since meaning is subjective, it cannot be generalized. What one person finds meaningful another may not.

23 It must be stressed that the occupation of selling second hand clothes was probably not the only source of meaning and purpose in her life. A detailed analysis of other occupations such as attending the universal church; doing household chores; caring for foster and grandchild and belonging to a burial society may have revealed other sources of motivation to keep going in the face of pervasive deprivation.

Table 14: Meaning and Purpose (M&P) of selling second hand clothes

THEME Core feature of M&P	THEMATIC DESCRIPTOR What was the unified interpretive response of M&P to OF?	THEMATIC STRUCTURE How was the OF experienced, understood & figured out? What outcomes, outputs or conditions were anticipated or desired as a result of OP? [1]	THEMATIC CATEGORIES What categories of ascription & intention existed in the data?	ELEMENTS IN THEMATIC SUB-CATEGORIES Which features of M&P impacted on OF & OP?
"Being poor should not take control"	*"...my things go right when I go to the Universal Church...."*	**SYNCRETIC ASCRIPTIONS**	Symbolic meanings	**Signification[2]:** she made sense of life events/stigma etc. i.t.o. her worldview
	"...then is when I value it (item of clothing) but if there is something wrong with it, I lower down the price...."	**SKILLED ASCRIPTIONS**	Perceptual meanings	
	"...I don't feel happy if I don't go to the second hands because I won't have anything on hand....."	**PRAGMATIC ASCRIPTIONS**	Affective meanings	**Resignation[3]:** based her actions on past experience; knew when to 'let go' or to expect an outcome as a result of learning
	"....doing business plays a positive role in my well being...."	**SELF ORIENTATED INTENTIONS**	Intrinsic purposes	**Expectation:** incentives, pay offs, what's in it for her & her h/h; justification for action
	"....nobody else will give us the little R10's...."	**INCOME ORIENTATED INTENTIONS**	Extrinsic purposes	**Goal orientation:** end point, marker or target towards which her action was aimed

Table 14: Explanation:

1. Ascriptions and intentions are features of the basics of occupation, linked to meaning and purpose, as described by Nelson and Jebson-Thomas (2003, p.111). Ascription refers to the value that is imputed, attributed or assigned to occupation. Intention refers to applying the mind and actions towards a particular outcome or goal. Syncretic, skilled and pragmatic ascriptions were identified and interpreted as pertaining in particular to the meaning and purpose that Dorcas attributed to selling second hand clothes. Syncretic referred to the reconciliation of different systems of belief; a fusion and blending of observances from different religious perspectives (lecture notes, Guma, 2004). Skilled referred to Dorcas's expert knowledge in trading second hand clothes based on prior learning over many years from childhood. Pragmatic referred to the matter-of-factness with which she reported dealing with her life experiences and the events surrounding second hand clothes sales including attributing her actions to instrumentalism and concrete cause and effect (Ikiugu & Schultz, 2006)
2. Signification: to ascribe meaning or significance to events that hinder or help function and/or subjective coherence
3. Resignation: to yield to

5.4.5 Findings: meaning and purpose

The findings depicted in Table 14 pertain to the meaning and purpose associated with selling second hand clothes and other related occupations. The findings indicate that Dorcas adopted a syncretic perspective in making sense and meaning of certain life events that unfolded in the social context of her particular occupational form " *...in church I lay down on my knees and pray for my life and if I don't pray my enemies comes back and my neighbours don't even greet me....they always do it (take advantage because she is mentally ill) , they always tell themselves that oh, she's no longer going to her church now I'll get her again and that is when they put their toilets in front of my door...*". She provided supernatural and pragmatic explanations for some life experiences "*... I didn't make myself ill, I became ill. I didn't ask for it...*" ; "*... my difficulties*

(poverty) add to my mental disabilities because I always think what is the cause of all this – is it because of evil sprit or is that's the way it should be as all of us have operation (look for work) and yet are not working, I only receive a grant.."; "*... my illness didn't make the poverty worse... you can think that I am working (a formal job) even though I am not and I can even do better than those who are working..*".

Dorcas was skilled in making perceptual meaning of second hand clothes as a particular occupational form. "*... I look at the faults of the clothes for example I look if the zip is functioning and all the buttons are there, then its when I value it but if there is something wrong with it, I will lower down the price ...*". Her occupational performance was motivated by self orientated and income generating purposes. She stated that the ostensibly meagre income, "*... the little ten Rands ...*", often made the difference between eating and not eating. Dorcas saw the purpose of survival as overriding the demoralising personal and health costs of keeping the business going. "*... if I don't sell clothes and just depend on the grant, I am unable to make enough groceries ...*". "*... we (Dorcas and Modloko) get tired but we are motivated by the fact that we have got nothing to lose but all to gain by walking so far ... we get clothes and even food for our children that way ...*". "*... but the business is not going anywhere ... sometimes there are too few customers and you return with only R10 for the day's work ... there is nothing better then if you do not have enough money because what if you do not have electricity or paraffin? ... You buy one of these two and the money is gone ... At the same time we are motivated to stay there because we know that nobody else will give us the little R10's we get there ...*". She attributed positive affect to being able to work "*..they (work efforts) make me feel like a better person and encouraged...*".

5.4.6 Discussion: meaning and purpose

Dorcas felt that **"...poverty should not take control.."**. As the unifying theme attributed to the meaning and purpose of her occupations, it suggests that Dorcas negotiated the interstices between competing needs within the occupational form on the basis of challenging the oppression of deprivation through action ie. she was determined to resist poverty by finding practical ways to adapt in securing a livelihood, irrespective how meagre the income was and how much it cost her in terms of time, effort and energy to obtain what she called 'the little R10's". Her main aspirations were to secure a decent house, to train her children to "survive in life like I have" and to put food on the table. She despaired that she only succeeded in the latter; given the fact that she had been on a waiting list for decent house for fifteen years and that both her surviving children were mentally unstable; a source of stress as Modloko indicated "*her children frustrate her a lot...*".

Pointing out that the poor do aspire, Appadurai (2004) argues that their conditions of existence (the social relations and structural inequalities within which they exist) and their past (for example, their cultural capital) limits the scope of their aspirations. Poorer women, for example, tend to hold aspirations for their children but not for themselves. They tend, according to Appadurai (2004), to recognise future possibilities for their children linked to the immediate aspiration of education but may not see these links as operating in their own lives. An uneven distribution of capacity to aspire also exists between men and women due to gendered divisions of responsibilities, economic roles, everyday relations and cultural practices. People living on the brink of survival may aspire to have two meals a day, with other aspirations being to look clean or wear clothes that will not bring shame on them in public. In brief, aspirational factors subliminally shape people's occupations.

The ability to aspire needs a road map for the future (Appadurai, 2004). Dorcas's health deteriorated over time and so did her aspirations for the business and for an alternative future. The possibility of securing a job, for example, acts as a dream towards which people may aspire; when unemployment is high, the dream may eventually die resulting in a multitude of psychosocial sequelae such as loss of identity, self esteem and compromised health and social behaviours. Dorcas had reached that point many years ago and had spiralled herself out of severe deprivation after a number of hospital admissions. She could see no future besides her daily hard work for small returns; returns that made the difference between eating and not eating. She reengaged with the meaning of previously mastered occupations associated with bartering and found purpose in making these tiny ends meet by being the main breadwinner. In so doing, she resisted the stereotype that psychiatrically disabled people are unproductive and a drain on the State by turning her disability grant into an asset for miniscule capital appreciation.

Conventional development wisdom is that disabled people are incapable of earning an independent living, are economically dependent and a quantifiable burden on society in terms of treatment and social security costs (Devereux, 2002, cited in Mitra, 2005). Devereux states that disabled people "survive by being cared for within their families or communities by institutional redistribution from the state (funded by taxes bid by the economically active) or by charity and begging which is a form of work … disabled people are not expected to participate in livelihood programs yet benefit from cash transfers" (*ibid,* p.6). While this is true for certain severely impaired, care dependent disabled people, the majority of disabled people are committed to and capable of participating in livelihood generation (Oliver, 1996). Practical and policy support of their burgeoning economic agency and

occupational performance would pave the way for inclusion and focussed productivity at a level commensurate with their residual and unfolding ability (Lund, Kleintjes, Campbell-Hall et.al., 2008; Seirlis & Swartz, 2006). In the next section, the performance of selling second hand clothes, the last component of the basics of the occupation is presented and discussed.

Table15: Occupational Performance (OP): selling second hand clothes

THEME Core feature of OP	THEMATIC DESCRIPTOR What was the unified OP response to OF?	THEMATIC STRUCTURE How was OP structured?	THEMATIC CATEGORIES What categories of OP occurred to support productivity ?	ELEMENTS IN THEMATIC SUB-CATEGORIES What tasks & activities were associated with active doing / OP (running informal 2nd hand clothes business) in context of OF?
"….I am doing efforts…."	*"….since I cannot wash my clothes so she is doing my washing and I am educating her…."* *"… I hire help as I am unable to do some other things then I pay her…."*	**SUPPORTED HABITUATION**	(Necessary & committed occupations) Activities of daily living	**Choring**: wash, cook, clean, shop
	"…we use this system…." *"… I have started some income generating ever since my mental illness started….."*	**SUPPORTED MARKET MAKING**	(Contracted occupation: selling 2nd hand clothes) Work activities	**Sourcing:** cold call, barter, (initially also bulk buying) **Transporting:** walk, carry, hitch **Storing:** sort, fold, pack, place **Preparing:** wash, mend, iron, fold **Valuing:** price or discard **Displaying:** sweep site, spread ground sheet, layout goods **Trading:** barter, give, sell, loan **Cash handling:** secure money, count, use, distribute
	"….there is no time to rest…." *" ….I'd rather just sit at my street corner…"*	**SUSPENDED RECREATION**	(Discretionary occupations) Leisure activities	**Restoring:** sleep, (re)create, **Relating:** God, living-dead, self, friend(s); neighbours

5.4.7 Findings: occupational performance

Table 15 pertains to findings on Dorcas's general performance of the contracted occupation of selling second hand clothes. It also addresses her necessary, committed and discretionary occupations as these were interwoven with the contracted occupation. Adaptive capacity is evident throughout her occupational performance domains. She did as much self care and home maintenance tasks as she could manage herself and delegated those she was unable to perform by either hiring someone or getting her niece to assist in exchange for paying for her education. *"…I wake up early in the morning , make porridge for them, clean the house then prepare the meal and there after go to the stand and I leave at five on the stand to prepare supper for my son as he doesn't have wife and then do dishes and afterwards go to sleep..". "… since I cannot wash my clothes she is doing my washing and I am educating her…she also does*

shopping for me and do some groceries for me…". "…someone I hired to help me out as I am unable to do some things, then I pay her ..".

Dorcas and Modloko formed a mutually beneficial working partnership that enabled both parties to gain financially from their informal business. Modloko had access to the benefits of Dorcas's disability grant. It enabled them to acquire products to barter for clothes without which it was unlikely that they would have been able to keep the business going *"…I give her (Modloko) paraffin and rice and other things when I receive my disability grant because she taught me business skills (how to adapt in view of impairments) …"* and in turn, Dorcas had someone who accommodated her impairments and assisted in practical ways when she was unable to function optimally. *"… she would be unable to endure the work if she had to do it without me because she is not a very healthy person…"."…I'm like her sister and she is now my sister. Not only do I help with her business but sometimes also with her household chores. Sometimes I come to check up on her and I find that she is ill and there is absolutely nothing to eat. I tell her to lie down a bit and I will clean her house for her and go alone to the street corner to make some money for her so that she can give something to the children…" ; "..we sell those second hands together by walking together …I assist her with carrying her stock, setting her stand..".* The partners went about making used clothes a marketable product by performing a series of tasks that took up a lot of their time. They sourced garments two days a week (cold calling and bartering) *"…sometimes they say 'we don't have money' before you even tell them that you are selling or bartering stuff.."* ; transported bags of clothes over long distances (walking, carrying, hitching); stored the bags in the small space of the dwelling; prepared the clothes on another day or two (sorting, washing, mending, ironing, folding); *"… you get home, you sift the clothes, take your wash tub and start washing right away..". "…Dorcas hires someone to do it for her at the charging rates of R10 to R20 which she usually pays when she gets her grant…" ; "… we don't fix very torn clothes … we just throw them away … the clothes must look unused even though they are second hand … we wash dirty clothes all the time, iron (using wrought iron heated on open fire) them before they are laid out at the street corner …"* ; and valued the items (pricing or discarding garments). She displayed goods in a particular way to attract customers (sweeping site, laying goods out) *"… the biggest challenge is the actual selling of these clothes at the street corner … we get attacked by dogs and we must clean their shit away before laying out our clothes .."* ; traded for three days usually over weekends (bartering, giving away, selling, extending credits and loans) and handled cash (security was an issue for Dorcas as she needed to hide her money from Noluthando and would end up forgetting where she hid the cash) *"… I count all the money that I receive from the clothes I sell and put it on the pocket, make change and handle my finance…".*

Dorcas reportedly did not participate in any social or recreational pursuits similar to those of other people in the community for example crafts, singing in a choir, burial society meetings and traditional feasts. Modloko thought it was because *"..Dorcas has a mental illness so she avoids social settings and too many questions.."*. *"... she is so busy she does not have time..."*. Her discretionary occupations were limited to sleeping, "resting" by sitting at her stand or in her dwelling and talking to friends. Although she used to go to church regularly this occupation lost its appeal during the study period for undetermined reasons *"...we always visit each other as close friends..." ; if I don't go to church for instance say a week my mental disabilities come back...I attended the Universal (church) but am taking a break now..."*.; *"... me I just like to sit by my stand..."*.

5.4.8 Discussion: occupational performance

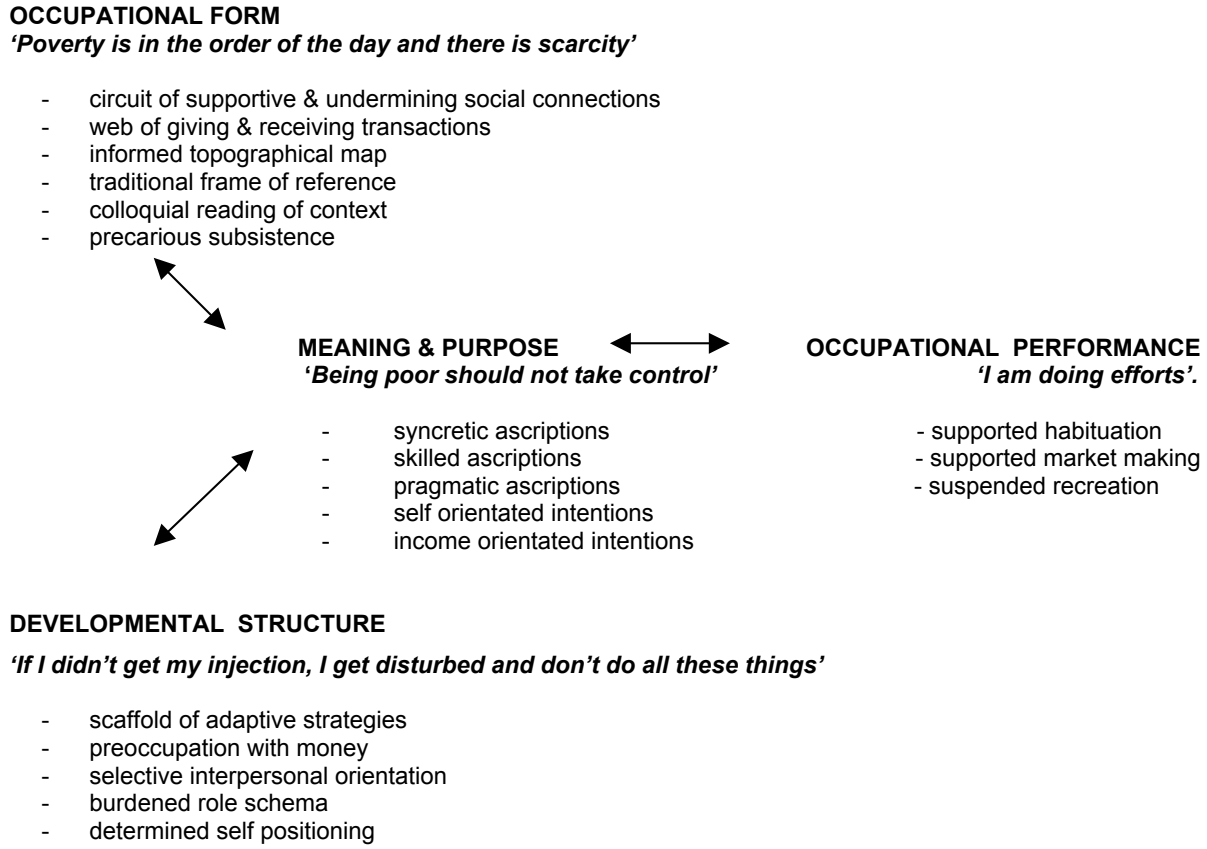
Occupational performance is, by definition, active. It involves "voluntary doing by the person in the context of the occupational form" (Nelson and Jepson-Thomas, 2003, p.111). After the person interprets the occupational form and wants to do something about it, an occupation may occur. Dorcas's response to occupational form was **"I am doing efforts"**. For her, effort entailed negotiating an under-resourced form; adapting to a deteriorating developmental structure (aging and a chronic mental illness) and finding meaning in the primary purpose of her life: her role as provider. This occupational performance response begs the question: what is disability? Living in structurally fractured and impoverished environments is as disabling as dealing with the functional implications of impairments because it restricts what people are able to do and therefore accomplish in accordance with their potential. Form determines what people are able to do as well as their ability to constitute themselves as change agents. This may particularly be the case when their health is compromised or when they are disabled. Du Toit (2005b, p. 24) suggests that while access to resources and capitals play a role in shaping what kind of agency is open to the poor the real challenge is to "engage with the felt and meaningful reality of stress, hopelessness, anger and despair and to exploring how the socially mediated sense people make of their own suffering further shapes their ability to cope and their prospects of escape". Dorcas's narrative provides some insights into her adaptive capacity in dealing with the lived realities she faced including the strategies she used to plot a way for herself in the midst of enduring deprivation and ill health.

5.5 SUMMARY OF CATEGORICAL AGGREGATION

Categorical aggregation enabled an in-depth analysis of each of the subcomponents of the basics of Dorcas's occupation of selling second hand clothes: form, developmental structure, meaning and purpose and performance. Figure 7 (themes: unique to Dorcas, ie are likely to

vary from person to person performaing the same occupation) and Table 16 (elements: likely to be universal, ie. based on activity analysis, these elements are inherent in the occupation of selling second hand clothes) summarise the preceding categorical aggregation by depicting the unified basics of Dorcas's occupation of selling second hand clothes.

Figure 7: Unified thematic descriptors of the basics of Dorcas's occupation of selling second hand clothes



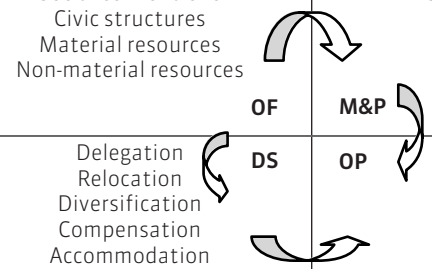
Both Figure 7 and Table 16 portray the complexity of ONE income generating occupation in the context of psychiatric disability and chronic poverty and illustrate how elusive the construct of occupation is when subjected to rigorous analysis[24]. The thematic descriptors of primary data categories reflected in Figure 7 addresses the research aim with reference to one participant. It portrays how Dorcas performed, viewed, orchestrated, drew meaning from and attributed purpose to the everyday things she did, in particular her primary contracted occupation. The interface between the various elements (refer right hand column of Tables11,13,14,15) operating within the basics of the occupation of selling second hand

24 Refer to discussion on occupation in Chapter 2, point 2.2.

clothes is depicted in Table 16[25].

Table 16: Unified elements of the basics of Dorcas's primary income generating occupation of selling second hand clothes

OCCUPATIONAL FORM (Table 11)	Actors Rules of exchange Topography Social conventions Civic structures Material resources Non-material resources	Signification Resignation Expectation Goal orientation	**MEANING & PURPOSE** (Table 14)
DEVELOPMENTAL STRUCTURE (Table 13)	Delegation Relocation Diversification Compensation Accommodation Isolation Encapsulation Modification Valuation	Choring Sourcing Transporting Storing Preparing Valuing Displaying Trading Cash handling Restoring Relating	**OCCUPATIONAL PERFORMANCE** (Table 15)



There were many activities[26] involved with performing the occupation of selling second hand clothes [OP]. Underpinning Dorcas's productivity was her ability to adapt the performance components in her developmental structure and to draw on prior occupational learning experiences [DS]. Her adaptive capacity was enlarged (and restricted) by the resources (or not) available in her occupational form [OF] and by the motivational push (and pull) of meaning and purpose [M&P]. Uniquely her own experience of selling second hand clothes, this summary of the data analysis nevertheless illustrates how the individual, the social and the structural co-constitute the construct of human occupation. It also hints at the possible focus of occupational justice[27] as facilitating the exchange between [OF] and [OP].

In the next section, four major ideas that organised the basics of occupation in the context of Dorcas's experience of chronic poverty and psychiatric disability are presented.

25 See Appendix 9 for cross case generalisation of core elements in basics of income generating occupations

26 See Chapter 2, point 2.2.1. A debatable point here is whether the elements reflected in the OP block are activities; sub-occupations (Nelson and Jepson-Thomas, 2003, p. 129) or related occupations. This conceptual disjunction illustrates how elusive the construct of occupation is and why its theorization remains an important priority in occupational science.

27 See Chapter 2, point 2.2.7

5.6 MAJOR ORGANISING IDEAS

Occupational form emerged as an intricate **communal foundation matrix**[28] within which Dorcas, as an individual actor, was able to function and meet the basic needs of her household by operating within a set of tacit rules. She assimilated this matrix and was assimilated into it as a member of the community over many years; it was a 'known territory', one in which she could function through self organisation and adaptation. Dorcas's personhood was defined by her membership of an organic, communal network of hierarchically defined relations including the living and the living-dead. She deferred to her elder brothers for domestic assistance and advice; entrusted her care to specific people when she became psychotic and relied on particular retail and bartering connections for the smooth running of her business. Her occupational performance was motivated by an interdependent, shared understanding of community as a way of life. This understanding was confirmed by the objective realities of the occupational form within which she operated. Dorcas learnt how to barter labour, goods and skills within an interdependent social network that operated to support the livelihood of the collective to which she belonged. She was able to remain productive despite her disability by resolving functional, financial and other life challenges through negotiating support as a member of an established network of distributed human capital; in particular a close, supportive business partnership. She was not, in her estimation, disabled. Her mental illness and other people's reactions to her psychotic behaviour was part and parcel of the way life was. The proactive use of the support systems within her occupational form helped her manage her illness behaviour, the demands of her business and the consequences of social stigmatisation.

Dorcas's was motivated, in part, by a **syncretic horizon of understanding**[29]. A mixture of traditional Xhosa and evangelical Christian beliefs helped her to ascribe meaning to her life events, occupations and the actions of others. The purpose behind her choice of occupations, in the context of limited opportunities due to structural and material constraints, was to comply with cultural role scripts for being a mother and breadwinner. She rationalised and adapted to the hardship she faced on a daily basis by firstly drawing on syncretic explanations for the challenges of chronic poverty and psychiatric disability and secondly, by drawing

28 Foundation matrix, originally described by S.H.Foulkes, refers to the unconscious processes through which individuals develop the interpersonal capacity to relate to networks and groups (Scholz, 2003).

29 Horizon of understanding refers to the perspectival background against and within which individuals act (Mkhize, 2004, p. 61).

on an internalised [30] work ethic and commitment to her responsibilities as a mother and breadwinner.

Her agency could be attributed, in part, to the **recapitulation of occupational genesis**[31]. She gave expression to her selfhood through the re-enactment of a role portfolio that she acquired as a child. This involved the performance of committed and necessary occupations associated with domestic maintenance and contracted occupations in the informal trade sector. Her economic agency and productivity in the execution of contracted occupations was based on skills acquired during childhood ie. she recapitulated income generating activities learnt as a child throughout her life. Her occupational performance was directed by rules, habits and skills acquired, amongst others, through the execution of subsistence orientated contracted occupations in rural villages. Destitute and mentally unwell later in her life in a peri-urban environment, she established herself economically by reverting to familiar occupations such as bartering second hand clothes. Managing a complex mental illness and competing with an over subscribed second hand clothing market, meant that she relied not only on her capacity to adapt but also on the support of her business partner without whom her achievements would not have been possible.

Dorcas maintained control over her functions (developmental structure) and structures (occupational form) by being clear about her motives and goals (meaning and purpose). The most salient pattern across the basics of Dorcas's occupation(s) was her **supported adaptive capacity** ie. her ability to perceive the need for change in what and how she did things in order to act with relative mastery within the constraints of her illness and poverty. This was made possible by drawing on and being embedded in particular supportive partnerships. She modified or adapted her occupational responses and choices with due consideration of available, albeit limited, personal, physical and structural resources and opportunities. The strength of this capacity, operating in very small circle of influence, was the cumulative result of experience with responding adaptively to occupational challenges over her lifetime. Her economic agency, restricted to a small cycle of exchange and range of occupations, was based on years of learning how to act with relative mastery by adapting, modifying or changing either physical occupational form or performance. Her adaptive capacity was regulated by the

30 Internalisation means that processes originally outside of people's control become part of their intrapsychological world (Mkhize, 2004, p.57).

31 Recapitulation of occupational genesis refers to the re-enactment of practical, activity orientated skills acquired during the formative, primary years of life (Mosey, 1970, p.133). The importance of early childhood education and further training and skills development as critical foundations for human and social development is affirmed by these findings.

state of her developmental structure at a point in time (for example during times of relapse or when she accessed skills training and practical support to sustain her participation) and the survival orientated motivation she derived from performing her occupations. In short, Dorcas was a problem solver but her ability to act on this was contingent on the support provided by Modloko and other role players within the ambit of her occupational form.

5.7 CONCEPTUAL ASSERTION

Drawing on cross case analysis and based on the evidence provided in this single case study, it is asserted that adaptive capacity[32] is an unrecognised form of agency[33] operating through human occupation in the context of chronic poverty and psychiatric disability. The participants in this study displayed agency to the extent that they were able to establish goodness of fit between available personal (individual), interpersonal (social) and environmental (structural) resources[34]. Structural and systemic factors determined the availability of physical and material occupational form through which participants could enact their agency. However, given the resource constrained context within which they functioned, their agency depended on the interface between their developmental structure and the meaning and purpose that was ascribed to occupational performance. Analyses of the basics of occupations that were orientated towards subsistence in the participating households revealed that choice (intentions) and opportunity (emergent in context) were co-ordinated in relation to the adaptive capacity of the individuals concerned[35]. While a resource constrained environment, beyond the control of the individual, restricted the occupational form at his/her disposal and therefore the range and scope of occupations that were performed, they nevertheless adapted their occupational responses to emerging opportunities in accordance with available

32 For definition see Footnote 18. Adaptation is the change in the person because of his/her active doing. It is the effect of occupational performance on the person's developmental structure (Nelson and Jepson-Thomas, 2003; Schkade and Schultz, 2003). It is used here in the sense of creative use of the environment and not in the sense of conformity (Mosey, 1970).

33 Agency refers to the "capacity of intention…that is, individuals through rational thought, free will, motivation or emotion, are able to direct their behavior or make particular choices" (Hayes, 2004, p. 179). It is argued here that the capacity of intention of disabled people and their households living in poverty is primarily directed at adapting to the press of occupational form (as opposed to pursuing their aspirations).

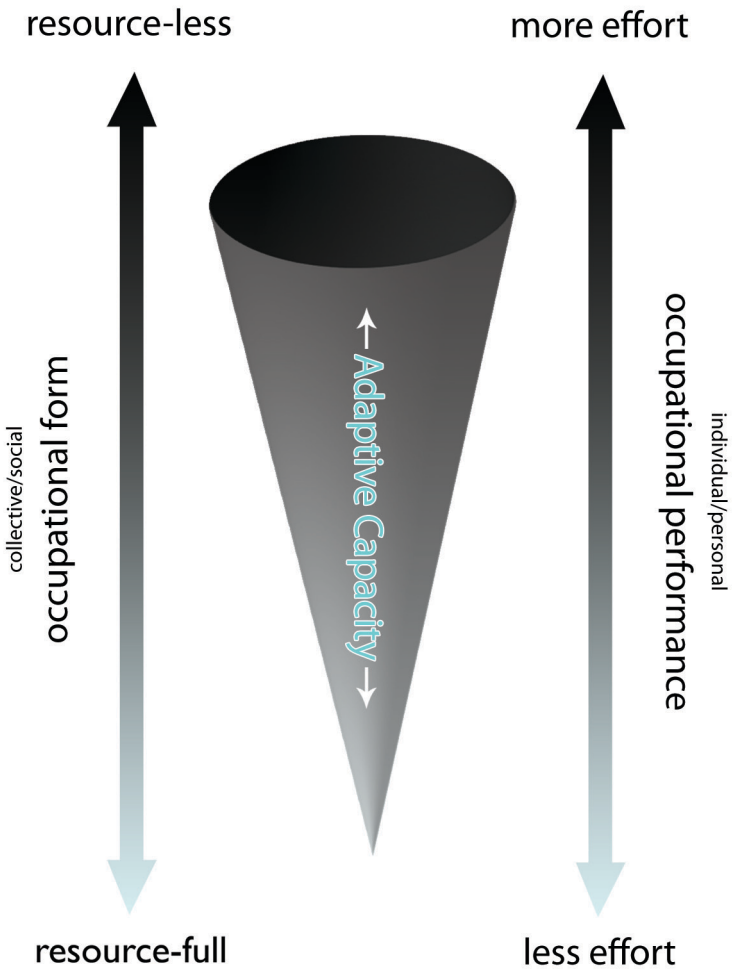
34 Dickie, Cutchin and Humphry (2006), in critiquing individualism in occupational science (and by inference occupational therapy models of practice) argue that occupations are "forms of action in which independent notions of structure and agency melts away. What takes their place is a form of relational action composed of habit and creativity (from personal and social sources) and the social and environmental contexts through which they operate and which they reshape" (ibid, 2008, p.164). While analysis of the basics of occupation in participating households confirmed the notion of occupations as forms of relational action; independent structure and agency did not melt away, they were evident in the adaptive capacity of individuals in facing the demands of poverty and disability. Habit and creativity were evident in the way participants synchronized and adapted their activities, tasks and roles to enable survival.

35 See Chapter 2, Figure 1, page 21. Note where choice and opportunity are positioned within the basics of occupation.

adaptive capacity[36]. The capability to perceive the need for change, modification, or refinement (adaptation) of an occupational response in order to respond with relative mastery varied from person to person depending as much on individual characteristics (including personality and health status) as on social and structural factors.

Figure 8 depicts the dynamics of adaptive capacity operating within the basics of occupation. Bear in mind, this diagram pertains to that which unfolds within a particular occupation ie. adaptive capacity can best be discerned by identifying the extent to which the doer perceives the need for change, modification, or refinement (adaptation) of an occupational response in order to respond with relative mastery AND ACTS ON IT. Knowing what and how to do something about the challenge at hand lies at the core of agency.

Figure 8: Dynamics of adaptive capacity in relation to the basics of occupation



36 For example, refer to Table 16 [DS].

The cone in the centre represents expanding or contracting adaptive capacity. The fewer resources that are available in the occupational form, the more effort has to be expended on performing occupation, the more adaptive capacity is required. Conversely, the more resource-full the occupational form, the more physical, structural and systemic support is available; the less effort is needed in performing occupation and the less likely the need for adaptive capacity because more opportunity, choice and support exists. Increased or decreased adaptive capacity occurs in response to the push or pull generated within the person's developmental structure and by the meaning and purpose attributed to occupation(s). If the person's developmental structure is compromised by a health condition, lack of skills or disability, his or her adaptive capacity may be restricted, decrease or fluctuate. If support, guidance and training are added to existing skills and abilities the capacity to adapt is likely to expand contributing to increased resilience and productivity.

Occupational therapists believe that humans demonstrate their volition, creative ability and agency through the things that they do (Mosey, 1970). Intervention is based on the premise that doing leads to change and that the locus and direction of change can be influenced by attending to the details of what is done objectively. This in turn influences what transpires subjectively. By enabling meaningful and purposeful occupation and creating opportunities to think through the processes and outcomes of occupational performance, the potential for awakening, directing or re-directing agency exists. Transcribed in memory as the practical consequences of prior actions, humans build up a repertoire of knowledges, skills and attitudes commensurate with their developmental structure (which includes volition, agency, creative ability etc.). These transcriptions are also shaped by the various contexts within which they live their lives; contexts which may or may not support exploration, learning and ultimately the development of human potential. In short, mediated occupation provides a substantive platform for shaping transcriptions that may influence dormant agency.

The seminal work of Macmurray (1991) on the self as agent, presents occupational therapy with a cogent theoretical rationale for its core belief in the 'wholeness' of humans as integrated personal selves who act in and on the world through occupation. Macmurray turns the relation of person and subjective self on its head: the cognito of 'I think therefore I am' is a function of 'I act and therefore I am'. For Macmurray, the person as agent takes precedence over the thinking, feeling, symbolizing and reflective self. He believes that volition and agency comes before cognition. The capacity of intention exists subjectively leading to thought that then directs action objectively. Humans intend something and then they think about it, then they act on it. Thinking is a function of the way humans experience things. Their experiences in turn

shape the kind of transcriptions laid down in memory which in turn influences the capacity of intention. Reflective thought serves an instrumental relation to purpose and action, not the other way round. We build intentional organizations of meaning by selective perception involved with everyday, moment by moment thought and other complex involvement of our developmental structure. This means a person continually selects and organizes information that links intentions operating in the moment. For example, if the purpose is survival, then the capacity of intention will be directed towards actions that operate in the moment; actions that emanate from transcriptions in memory as the practical consequences of prior actions. Transcriptions predicate the nature of further actions. This is why a passive person has a different story to tell than an assertive, active one and why poverty and disability affect different people differently.

5.8 CONCLUSION

Using the basics of human occupation as a lens, this chapter has presented the story of one woman who has lived her entire life in poverty. Despite having a chronic mental illness she maintained a steady level of productivity in contracted occupations such as selling basic commodities and second hand clothes. While she acknowledged her impairments, she did not see herself as disabled by the relational context within which she functioned. An analysis of the basics of her primary contracted occupation indicated that she subsumed a disability identity into her roles as friend, business partner, provider and parent. She drew on prior learning to run her business, relied on a small social network to support her during times of relapse and hardship and found ways to adapt her occupational responses in accordance with her fluctuating health status and the demands of the context. While her story is uniquely her own, it illustrated the potential of psychiatrically disabled people firstly as economic actors in the informal sector and secondly, as contributors towards survival strategising in poor households. In addition, the chapter highlighted the role of the informal relational economy[37] in supporting the sustained participation and productivity of disabled people and argued that adaptive capacity, operating within the developmental structure of the individual and manifest in occupational performance, is an under-recognised form of agency.

37 See Chapter 4, footnote 42.

CHAPTER 6: CONCLUSION

6.1 INTRODUCTION

The purpose of this study was to obtain information about the occupational performance of psychiatrically disabled people living in chronic poverty so as to guide the focus of occupational therapy mental health services and advance theory development in occupational science about the construct of occupation. This concluding chapter will briefly discuss the limitations of the study followed by four recommendations that address the purpose of the study. It concludes with a brief resume of the dissertation as a whole.

6.2 LIMITATIONS

This study has many limitations which have been alluded to throughout the report. The logistical challenges involved with gaining access to the community and people's lives, while indicative of the realities of their circumstances, nevertheless detracted from the efficiency with which data were gathered. The lack of basic amenities such as telephones; disruptions associated with civil unrest and lack of privacy in cramped dwelling spaces compromised the research process. Personal limitations in terms of academic and service workload meant that the study was done part time and after hours, detracting from the richness that immersive exposure would have yielded. The research was also emotionally taxing which increased the potential for bias as did my status as cultural outsider. Cross cultural and class differences as well as language barriers between the researcher and the research participants posed methodological limitations on the type, depth and breadth of data that was gathered; the rigour of translations and transcriptions that occurred and the quality of meaning interpretations that were made.

Although conceptual assertions are made about the insights gained, the findings cannot be generalised. The small sample consisted of poor people from a particular ethnic group in a particular geographical setting. Poverty exists across all race groups in South Africa. The findings must therefore be tempered with due recognition of bias and particularity. They pertain to individual circumstances in a particular context at a particular point in time. The research participants had a chronic psychiatric disorder linked to periodic episodes of psychosis. The findings are not therefore applicable to less severe, common mental illnesses such as anxiety, depression and post-traumatic stress disorder. The theoretical limitations of the study lay in the complexities of defining the three primary constructs under investigation. With little consensus in the literature, it is difficult to arrive at clear-cut conclusions about the dynamics between occupation, chronic poverty and psychiatric disability in individual lives

because these constructs are elusive in terms of definitive parameters and unfathomable in terms of scope and impact. At best their combined influence can be subjectively experienced and qualitatively described. While the case studies serve as a source of understanding about the dynamic interaction between mental illness and what people who live in chronic poverty do everyday, any theoretical extrapolation must be tempered with due consideration of the context from which it originates.

6.3 RECOMMENDATIONS

Undoubtedly most disabled people living in poverty want to be self-reliant so that they can reach their aspirations and care for their households. Their ability to do this is thwarted by many different factors. Still, every small change and shift towards meeting peoples' hope for the future can be counted as a step forward. The dimensions of chronic poverty are so widespread and their relief at present so limited that it is imperative to use every possible means of support to effect change. Four recommendations towards this agenda are presented.

6.3.1 Cautious extrapolation of research insights to mental health occupational therapy practice

Smith (1999), speaking about the experiences of Aboriginal people in being researched, points out that the power of colonizing research is not in the visits made by researchers to communities, the outcomes of the fieldwork or the rude questions that participants are asked. Rather, it lies "in the creeping policies that intrude every aspect of our lives, legitimated by research, informed more by ideology" (*ibid,* p. 3). What ideology may inadvertently be perpetuated or imposed on psychiatrically disabled people living in poverty through the insights that flow from this study? For example, is it possible that mental health occupational therapy services and policies, ideologically shaped by the 'best intentions' of occupational justice, may creep uninvited into their lives, changing circumstances that they themselves have not prioritised? Without the power of inclusion, psychiatrically disabled people will have little influence on the kind of occupational therapy services that are indicated to help them address their circumstances. With this caution in mind it is recommended that:

- assumptions about human occupation in the context of chronic poverty and psychiatric disability have to be critiqued - inclusively, iteratively and reflexively. Failure to do so leads to professional complacency in the mistaken belief that, as occupational therapists, 'we know' - and therein lies the potential for oppression. We don't know and therefore have to remain open to the possibilities of learning from the people we serve.
- psychiatrically disabled people are included in occupational therapy mental health service development initiatives in poor communities. This study has revealed the extent

to which participants were able to navigate the occupational form within which they operated. Disabled people are therefore in the best position to disseminate knowledge about their lives especially contextual knowledge that will inform the kind of services that they themselves have identified as critical for their development.

6.3.2 Affirmation of culture in occupational therapy practice, research and education.

Individualism and independence, the hallmarks of self actualisation, permeate occupational therapy literature and continue to inform, albeit tacitly, the interventions that clinicians offer service users in South Africa. Culture is often 'tagged on' as one of many factors to consider during occupational therapy intervention - as if it exists compartmentalised in the lives of people who require support in dealing with the challenges of living with disability. This study confirmed the centrality of culture in what people did everyday and revealed how occupational performance was scaffolded by the values of interdependence and reciprocity. The affirmation of culture in local occupational therapy practice, research and education may occur by:

- looking at the ordinary and the contextual and not primarily at the pathological as is prone to happen when a medical gaze is used to discern the challenges that people face. People are first and foremost people before they are patients, clients or service users. While extant professional literature provides a solid theoretical basis from which to proceed, it should be critiqued, deconstructed and re-formulated with due consideration of the normative values, beliefs and practices of local people.
- acknowledging the multi-lingual and multi-racial profile of the nation and by creating space for learning across and about many competing knowledge systems. Culture must form the basis on which professional epistemology is constructed and from which education, service, research and development action proceeds. This may mean appreciating that the mental, the spiritual and the emotional are not separate from the material; that knowledge is not just a commodity, it is also wisdom passed down from ancestors; and that customary law, moral precepts, values and beliefs are based on oral as well as written traditions.

6.3.3 Increasing the focus on poverty and disability in occupational therapy and occupational science

While the development agendas of disabled and poor people go hand in hand, there has only recently been evidence in the occupational therapy literature that these two agendas belong together and that they deserve particular attention by the profession (Kronenberg,

Simo-Algado & Pollard, 2005; Watson & Swartz, 2004). According to Priestley (2006, p. 20), the political activism of disabled people has led to "new ways of thinking about disability in a social world". Coleridge (2001), writing five years earlier, points out that disability has not filtered into certain significant international policy documents such as the Poverty Reduction Strategy Programme (PRSP) (World Bank, 1999) and the Millennium Development Goals (United Nations, 2000), both aimed at mobilising co-ordinated international efforts for the reduction of poverty. According to Coleridge (2001), the Source Book to the PRSP does not reflect the huge shifts that have occurred in thinking about disability in recent years. In both these documents disabled people are placed, along with children, old people and the chronically sick in the category marked as "not able to be economically active, in need of special care and welfare". Coleridge argues that disabled people are, in the eyes of the World Bank Source Book, not participants in development but rather objects of charity. He points out that if someone is the object of charity, they are stuck in an imposed role from which there is no escape. The problem of exclusion, amongst others, is the cycle of voicelessness that is the burden of poor and disabled people alike. Occupational therapists, as allies of psychiatrically disabled people, can:

- advocate for their inclusion in development programmes. The cost of not including disabled people in the economy is shortsighted (Harnois & Gabriel, 2000; Coleridge, 2001). Handing out welfare to increasing numbers of people is unsustainable. Supporting their efforts to become economically active is a viable alternative. This study has shed light on the intricate balance of factors operating within the basics of some income generating occupations in the informal economic sector in a peri-urban settlement. Further investigation into the basics of occupation in other contexts is indicated in order to build a body of knowledge about the needs of vulnerable people trying to make a living and the ways in which they adapt to their circumstances through the everyday things that they do. Knowing more about occupation in the informal economy will equip occupational therapists in promoting the economic empowerment of disabled people living on the margins of society.
- lobby for increased state expenditure on work preparation, vocational rehabilitation and reasonable accommodation of disabled people in the workplace. Occupational therapists have an established practice record in this field. By contributing their expertise to community based poverty alleviation initiatives, they will provide much needed practical support to workers. This will require a shift towards the community based rehabilitation (CBR) approach (ILO, UNESCO, UNICEF, WHO, 2002). CBR, as an integral part of social, economic, cultural and political development, must not be compared with other forms of individual rehabilitation. It is about inclusion, breaking

down barriers to participation, changing attitudes and collaborating with people on the ground in finding solutions to their unique challenges.

6.3.4 Promoting people-centred development through occupation

This study has highlighted the adaptive capacity of psychiatrically disabled people and their households. Since development is a natural, ongoing process found in all living things, it cannot be created, engineered or done to others from the 'outside'. Information, knowledge and skill alone will not precipitate the unfolding of human potential and agency. Effective development intervention must be an open-ended process in which response-ability to emerging challenges is sought (Kaplan, 1999). Capacity building occurs when people come to understand themselves; identify their own development strategies and recognize ways of accessing resources. People-centred development through occupation will be promoted when occupational therapists:

- become politically literate, active and engaged with the removal of barriers that restrict occupational performance. Being 'present' rather than 'dominant' when working in the type of contexts described in this study, keeping conversations and actions focused on mutual learning and solution generation, and being committed to the decentralization of responsibility and authority to the people being served will increase the impact of occupational therapy.

A conceptual assertion was made that adaptive capacity, evident in the ordinary things that people do everyday, is an under-recognized form of agency. It was suggested that people learn through personal experience which, in turn, is transcribed in memory as the practical consequences of prior actions and that these transcriptions predicate the nature of further actions; actions which may perpetuate or alter particular patterns of living. To understand these actions we must learn more about the form, process and mechanics of human occupation. It is recommended that occupational scientists:

- continue to articulate what they believe the basics of occupation to be and subject the identified components to rigorous research. This study confirmed both the elusiveness and value of the construct of occupation. It illustrated how complex the ordinary things are that people do everyday and that human endeavors are mirrors of multiple layers of reality. These layers warrant focused investigation and description in order to promote evidence based practice.
- turn their academic attention to the occupational human in the context of poverty. Occupational science literature to date reflects the ideology of the developed world. Poverty creates a particular set of circumstances in the lives of the majority of the

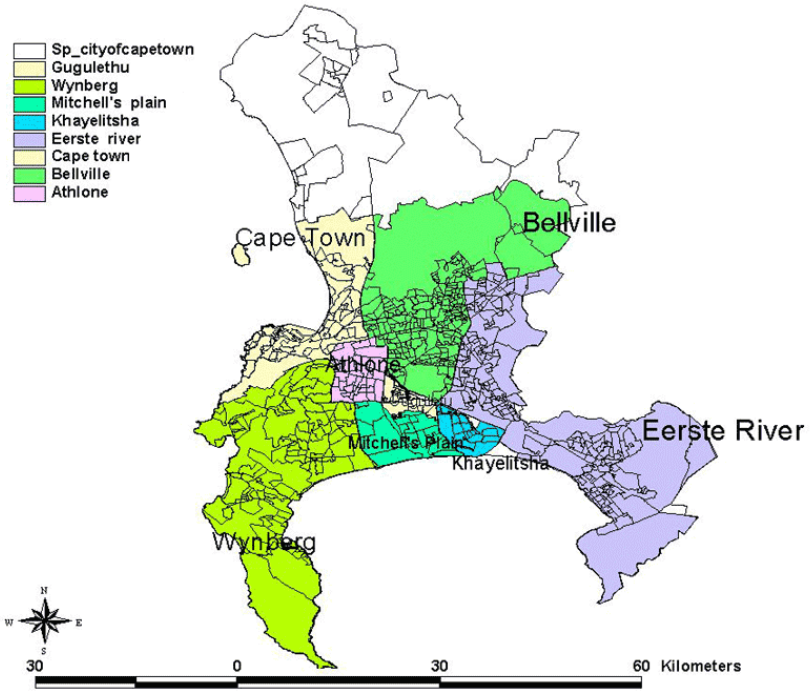
world's population. Occupational science will serve the moral obligations of social redress when it demonstrates solidarity with and commitment to the struggles of the oppressed by the kind of knowledge that it generates.

6.4 CONCLUSION

This study revealed that psychiatrically disabled people living in chronic poverty contribute in various ways to the vulnerability and survival of their households. While their illness behaviour during periods of relapse increased the risk of financial loss and social sanctions, they nevertheless contributed to household livelihood during periods of remission through a range of practical and attitudinal strategies that were evident in their occupational performance. In order to secure some benefit for themselves, household members including the disabled person devised ways to maximise the opportunities that did come their way. Looking at the ordinary things psychiatrically disabled people did everyday revealed their adaptive capacity, which, albeit fluctuating in scope and quality over time and from person to person, enabled them to act with relative mastery when dealing with the challenges of deprivation. They played an important role in the household by either providing a regular income through the disability grant, by being a source of additional labour or by pursuing occupations that generated augmentative incomes. The findings suggest that the individual, the social and the structural are co-constituted in what people do in a resource-constrained context. The fewer resources that are available in the occupational form, the more effort is needed to perform occupation and the more reliance is likely to be placed on the informal relational economy. This understanding of the basics of human occupation in the context of chronic poverty and psychiatric disability expands current descriptions of the construct in the professional literature and warrants further investigation by both occupational scientists and occupational therapists.

APPENDIX 1A: REGIONAL MAP

APPENDIX 1B: CAPE METROPOLE MAP



APPENDIX 2: ORTHOGRAPHY

Source: interview data; MacGregor, 2002

ISIXHOSA TERM	MEANING	ISIXHOSA TERM	MEANING
Amadlozi	ancestors	**(i)Inthlombe:**	therapeutic séance
Amafufunyane	Idiom for distress, phenomenon or experience of being bewitched, spirits speaking from the abdoment	**Igqirha**	a healer
Amandla	power	**Ithongo.**	patrilineal ancestral spirits
Amaphupha	dreams	**Idini**	a ritual sacrifice (goat or cow) at times of transition in life cycle
Amaxhwele	herbalist (inyanga in Zulu)	**Idliso**	bad spell/ poison
Amayeza	medicines from hospitals and medicinal treatments such as herbs and ointments from herbalists	**Inkambo**	becoming, 'life journey'
Ehlaleni	in the community	**Ingoma**	song or melody
"Gooi-gooi" **Umgalelo**	credit association (stokvel)	**Inkam-kam**	'income': money obtained through social grants
I'camagu (noun)	reverential term for 'amen' or 'let it be so'. Ritual usage means 'thanks be to you in the name of the shades"	**Impundulu**	a witch familiar who moves like a lightening bird
Inkenkqe	emotional upheaval	**Impilo**	health (noun)
Ingqondo ziyamshiya	mind has gone away (interactions with spirits)	**Indodla (iPenshini)**	pension
Imibono	visions	**Isifo**	vulnerability to misfortune and disease
Impepho	dried flowers burned for their aroma during rituals	**Ixhwele**	herbalist
Indiki	possession by alien spirits, who as a result of not receiving a proper burial, occupy the bodies of living men.	**Izilo**	shades who take on the form of animals
Igqirha **(isangoma in Zulu)**	diviner, traditional healer	**Izinyanya (pl)**	ancestral shades ityale (s) ancestral shade
Ingqondo ibuyile	my mind is returned:	**Isiko (s), amasiko (pl)**	customs
Ibulawo (n):	foaming medicine of the shades, taken orally and used as body ointment to bring communion with shades	**Impundulu**	birdlike familiar attacks body causing mental illness
Imithambo	veins in the head	**Imilingo**	magic
Ikhaya	home in rural area	**Indlu**	abode in city

Ixhala	anxiety	**Iingqondo ziyamshiya**	madness, the 'mind has gone away'
Iinerves	feelings of distress, anxiety, tension	**intlonipho**	prescriptions for married women: cannot use certain words or enter certain spaces
Isithetho	customary practice	**Isiwasho**	sangoma's herbal medicine
Intliziyo ibuhlungu	my heart is painful	**Imali**	money
Idliso	bewitchment by poisoning	**Ibuhlungu**	it is painful
Istress	stress	**Inkenkqe**	emotional upheaval indicating a call to become a healer
Kunzima	'it is heavy' (sad)	**Mamlambo**	familiar spirit who is mother of the river
Labola	marriage payment for a bride	**Malume**	uncle, mother's brother
Mlungu	white person	**Ndineinerves**	I have nerves
Nyanga	herbalist	**Phehlelela**	to train (a novice)
Sangoma	Zulu traditional healer	**Shebeen**	bar/tavern
Tsotsi	thug	**Umlaza**	ritual impurity
Qubula	the root problem is taken from the person for example the idliso may be taken from the body by the teeth of the diviner who produces maize size seeds as evidence of the cleansing	**Phuza amanzi**	to draw water slowly into the mouth, meaning to accept
Umthandazeli **Thandazela**	a person who prays for someone or to pray	**Ukufa kwabantu**	diseases of African peoples
Uyagula	to be ill	**Umkhuhlane**	illness due to natural causes
Ukuthakatha, ubugqwira	refers to both witchcraft and sorcery	**Ubuchopo**	physical brain
Ukuthwasa	training process to become diviner	**Ukungabikho zingqondweni**	to be out of my mind not clear thinking
Ukuphazamiseko ngengqondo	disturbance of the mind (disruption of its order)	**Ukugula** **ngengqondo**	an illness of the mind
Umzi	homestead in rural village	**Ukuhlonipha;**	to give customary respect
Ukuphila	to live; to be well	**Umgidi**	social gathering to celebrate circumcision
Ukuphangela	earning, working, employment	**Ukusebenza**	to work
Umkhaya	people from our home area	**Ukuthwebula**	when person has been taken by an aeroplane of the iketshi (witches), the person then becomes a zombie
Ummelwane	neighbour	**Umoya umdaka**	evil sprits
Ukuthwasa (v) , intwaso (n), 'thwasa (abbr)	to be in process of change. Applies to seasons and moon	**Ukuhlahluba**	telling as in drawing prophecy from the Bible
Umhlwa	evil omens	**Uthikoloshe**	a familiar spirit , short hairy man with large penis
Umthandazeli	prophets of independent churches	**Umeqo**	encounter with an evil spirit, a hex / curse
Ukunyamazela	to endure	**Ukukhathazeka**	worried
Uyacinga kakhulu	thinking too much	**Umkuwetha**	initiate
Ukuthwasa	initiation to become a healer	**Umqombothi**	traditional beer
Ukuhlupheka	to be poor or to be troubled	**Ukucebisa**	to give advice
Umasingcwabene	burial society	**Ukuba nexhala**	anxious
Uphambene	mad	**Ukulawul'amaphupha**	to relate to dreams
Ukugula	to be sick	**Ukufa okumhlophe**	a white sickness, synonym for intwaso

UPphazamisekile	disturbed	**Ubuthakatha**	malevolent witchcraft
Ucabamane	psychotic	**Ukugula**	all sicknesses
Ubhuti	circumcised man	**Umbilini**	Literally intestines. Used metaphorically by those called by shades to refer to feelings of pain, anxiety, rapid heart beat in chest and unsettled stomach
Ukuvumisa	when healer or diviner speaks out interpretations of what is seen in the bones	**Umvelinqangi** **God the Creator**	the first One who came before existence, the Creator of everything . The ancestors have gone to the world where this being is

APPENDIX 3: MEDICAL DIAGNOSIS OF PARTICIPANTS

Clinical records and files of the participants were inaccessible either because none existed; access was denied for confidentiality reasons or because the records were archived in a hospital in another Province. The following summaries are based on information gathered from interviews with staff at the mental health clinic attended by participants; ongoing mental state assessments done by the two occupational therapists/ researchers and from information on the participant's clinic cards (personally held). The associated features describe the behaviour that was observed during prolonged engagement with the index person for the duration of the study; self-reported symptoms and reports from key informants in the household. While acute episodes of psychosis occurred for each of the participants during the study period, most were in remission with negative symptoms accounting for varying degrees of morbidity.

NAME (pseudonyms)	**DIAGNOSIS DSM-IV-TR** (APA, 2000)	**ASSOCIATED FEATURES**
Siyanda Kamana	Schizophrenia	Flat affect, alogia, avolition, abulia, social isolation, neuroleptic medication exacerbates negative symptoms. "…I have disturbed functioning of my thinking…. sometimes you have negative thoughts and end up being backwards; I I cannot follow instructions or concentrate….I do unusual things…" "….when the sickness arrives he will stop doing things half way and just stare… when I I talk to him he just stares and won't say a word; at night he keeps walking up and down…"
Vuzi Bekwa	Bipolar 1 Disorder	Distractable, pressure of speech, irritable, very poor judgement, lots of joking, expansive mood, increased sociability alternating with days of sleeping and lethargy "…some people can read through me… my mind races…I get irritable and angry quickly…. I break things "; "…. he gets up at 4am in the morning and we find him scrubbing in bins, he brings the dirty, rubbish bones home and wants to cook them and when we stop him he throws stones at us…. Sometimes he lies on his bed and stares even if the rain is falling from the roof straight on him… he just stares at the water…"
Dorcas Somngesi	Bipolar 1 Disorder	Stubborn, irritable, labile mood, agitated and restless, flight of ideas "…I am very restless, I walk and walk, I cannot sit still….I pull off my clothes when I get sick and run around outside…. I refuse to eat and only survive on water…
Sesetu Nombewu	Neuropsychiatric disorder. Epilepsy (not a mental illness)	Belligerent, labile mood, over effusive and disinhibited behaviour, impaired judgement. "… she destroys our household belongings…. She breaks plates throwing them at her sisters…"
Fuzile Sojolo	Head injury with alcohol induced psychosis	Irritable, labile, impaired judgement . "… he will become impossible.. starts having a violent episode when he is drunk, he cannot tolerate noise… he sets fire to everything…"

APPENDIX 4: PHASE 1: SYNOPSIS OF PDO STUDY FINDINGS

(Watson , 2005).

DEMOGRAPHIC PROFILE OF PHASE 1 SAMPLE

A sample of thirty two households were surveyed during Phase 1 of the study (see Table 1). Although we set out to survey 15-16 people who had either a history of mental illness or an intellectual impairment only 11 met the inclusion criteria. The average age of the psychiatrically disabled people surveyed was 36.5 years (age range was 21-55 years) and included three females and eight males (see Table 4). Five of these individuals were purposively selected for the Phase 2 study.

GENERAL DEMOGRAPHICS

Table 1 provides general demographic details in terms of gender, age, heads of household and number of people per household.

Table 1: General demographic profile

CHARACTERISTIC	SURVEYED HOUSEHOLDS (n =32)
Gender	M en: 4 Women : 28
Age	Head of household: Average age: 50. Range: 30 – 74 Disabled person: Average age 33.85. Range: 9 – 78
Average number of people in household	7.5 Range 3 – 14
Disabled person head of household	11 Gender- 10 female
Relationship of head of household (HoH) to disabled person	Mother = 15 Others: Spouse, child, sibling, mother, grandmother, aunt, great-uncle, cousin, friend

Two figures are of note here. Firstly the average number of people per household is higher than the 5.35 figure presented by the Cape Town Equity Gauge Project (2002). This may be due to the small sample size and that a different definition for 'household' was used. Secondly, women outnumbered men as heads of household at 84.8% of the sample. Household structures and child caring patterns were very complex in the sampled households with women, 25% of them disabled, taking on multiple roles as primary carers, heads of household and principal breadwinner. The women in this sample had little education (60% had five years or less of primary schooling), no job training and few employment opportunities. The main source of income for the women who had previously been employed was domestic work in Cape Town. The jobs were not anywhere near where they lived which meant that they had

to pay transport costs, further depleting their wages. None of the women were employed at the time of the study, although thirteen were occupied with some form of income generation (40.6%) either from their homes (28.1%) or pavement stalls (12.5%).

Of the four men that headed households, one was employed part-time, two worked occasionally (as gardeners), and the fourth gardened at home and sold his produce to neighbours. None of them had been able to find a more permanent job as a gardener. They obtained casual gardening jobs by going from house to house in the suburbs of Cape Town. In some households there were adult children who were not working. The Focus Group participants gave a lack of employment opportunities as the reason for not leaving home as well as the shortage of housing. In four of the households alcohol abuse was reported as a problem.

DWELLINGS

Table 2 captures information about the dwellings in which the households lived providing an indication of general infrastructure and security.

Table 2: Dwellings

CONSTRUCTION	FACILITIES	NUMBER IN STUDY
Shack (informal dwelling: offcuts of wood, cardboard & corrugated iron	TOTAL	14
	Poorly constructed, old and cramped	12
	Spacious, furnished and established	2
House (formal dwelling: "breeze" brick and mortar with asbestos roof)	TOTAL	18
	Basic two roomed, un-plastered, toilet & running water outside	15
	Reasonable construction, some plaster, toilet and/or running water indoors	3

LEVEL OF EDUCATION (HEADS OF HOUSEHOLD)

Table 3 describes the level of education achieved by heads of household providing some indication of their access to schooling during the apartheid era when segregated education (called 'Bantu education') invariably meant inequitable allocation of resources.

Table 3: Education (heads of household)

Grade of education achieved	9	8 & 7	6	5 & 4	3	Less	None
H o H	1	3	6	8	3	3	8
Av. Age	45	50	56	45	43	53	55
D P/H o H	1	1	2	2	1	1	2

DP = disabled person HoH =head of household

The average number of years schooling for the 24 heads of household was 4.92 years. This compares to the reported educational level of 5 years for 'always poor' urban adults in Kwa-

Zulu Natal recorded in 1993 (The Chronic Poverty Report, 2004, p. 97). The average adult female illiteracy rate for South Africa was 15.4 % for the year 2000 and 14.0 % for men (Ibid., p.101). The sample is too small and diverse to generalise but it is obvious that the average level of achievement is low and would be a limitation for work seekers. There is no discernable pattern here to suggest that age might be related to the level of education achieved. Disability did not appear to have influenced the number of years of schooling.

HEALTH CONDITIONS

Table 4 depicts the spread of health conditions amongst the Phase 1 sample. It must be emphasised here that while impairment and disability are not synonymous, they may or may not be co-determinant. In identifying the health conditions, Table 4 does not indicate the associated impairments that were evident in a range of body structures and functions nor does it indicate the particular activity limitations and participation restrictions experienced by individuals.

Table 4: Health condition

HEALTH CONDITIONS & IMPAIRMENTS	NUMBER n=32
Bi-polar disorder	1
Cerebral Palsy	3
Deformities from old burns	1
Club feet	1
Diabetes	1
Epilepsy	3
Head injury	2
High blood pressure	2
Intellectual impairment	4
Organic brain syndrome	1
Poliomyelitis	1
Rheumatoid arthritis	2
Spinal injury: paraplegia	1
Schizophrenia	10
Stroke:CVA	2
Tuberculosis (on DOTS)	2

NB: Co-morbidity between conditions did occur.

The majority of disabled people were receiving a social security grant (90.09%). This meant that they were considered either so severely disabled as to be in need of special care or so severely disabled as to be unable to support themselves financially. The incidence of HIV/Aids was not recorded and never mentioned by participants, other than in one household, where the interviewees' eldest daughter had died of Aids.

HOUSEHOLD ASSETS

Most of the appliances in people's homes were gifts from family members bought during more prosperous times. The most favoured appliance was the television (65.6%), followed by the refrigerator (62.5%). A television set was regarded as an important possession because, according to respondents in the focus groups, it kept the family entertained and informed. Fridges served the dual purpose of storing food and preserving goods for sale. Most households cooked with paraffin. When house dwellers were asked if they used the ground around their property to cultivate vegetables/food, they said that there was no money for seed.

Table 5: Household assets

TYPE OF ASSET	TOTAL n=32
Water on tap	**26**
Electricity	**23**
Toilet (on site or on plot)	**20**
Hotplate or stove	**13**
Fridge (plus 2 freezers)	**20**
Television set	**21**
Radio	**5**
Iron	**4**
Kettle	**6**
Helpful neighbours	**13**
Church assistance	**3**
Supportive relatives	**5**
Helpful boyfriend	**2**
Ground around dwelling (growing food eg spinach).	**3**
Cell 'phone	**4**
Burial policy	**21**
Grants:	**29**
Child Support	**4**
Care Dependency	**7**
Disability	**21**
Old Age Pension	**1**

The grant uptake, included as an asset because it was a regular source of income, is noteworthy (90.6%). Burial society subscription was very important with 65.6% reporting belonging to one. Only eight families (25%) received a child support grant and no family had more than one grant, although some were eligible and had made applications (18 families that included eligible children under the age of ten years, 56%). There were people in the sample who did not have disability grants, although they appeared to be eligible with long-standing impairments or a health condition that was severe enough to prevent the person from working. It is not possible to acquire a grant without the necessary papers such as birth certificates and identity documents which were unavailable in a number of the households. Knowledge of the grant application process and procedures was poor. The dilemma people faced was how to find the money they needed in order to get to the place where they had to apply for identity

and other documents, and in some instances paying for these to be processed.

EMPLOYMENT AND OTHER INCOME GENERATING ACTIVITIES

Tables 6 and 7 provide an indication of the access households had to financial gain.

Table 6: Employment: head of household

A) AT PRESENT	NUMBER
No steady income other than grant(s)combined = 46.8%	13
Employed (part-time)	2
Self-employed	4
Small self generated income (e.g. home sales)	9
Another source of income e.g. boyfriend; relatives	4
Total	32
B) IN THE PAST	
Employed (37.5%) combined = 84.3%	12
Self-employed (46.8%)	15
C) NEVER WORKED (15.6%)	5
Total	32

NB: This includes disabled people that head households
Self employed = regular small business Never worked = irregular small self initiated projects

There was little variety in the type of work that people had done in the past, or what they were still involved in: men were employed as gardeners, the women did domestic work. A number of women had sold meat in the past or were still doing so. Some people were altruistic in their choice of occupation for example running a “creche” for a few children in their dwelling so that the mothers could go to work. The only ‘fee’ was a contribution for electricity.

All the ‘household economic strategies’ listed in Table 7 were aimed at supplementing a grant, (sometimes only bringing in an extra R75-R160 per month), required start up and maintenance financing. The entrepreneurial spirit that inspired these different ventures faced a number of barriers. Participants reported that they had to abide by certain unwritten business rules in which competition was not tolerated. If they marked their prices up to make more profit they would be socially censored.

Table 7: Type of income generation: Head of household (past or present)

TYPE OF INCOME GENERATION	NUMBER
Gardening and/or selling vegetables	3
Selling sheep's heads and feet	2
Selling Chicken	1
Selling Umqomboti[1] and/or beer[2]	3
Collecting cardboard	1
Selling intestines	1
Selling cigarettes	1
Selling cleaning materials	1
Selling biscuits and/or chips	2
Selling second-hand clothes	2
Selling cleaning materials	1
Selling paraffin and ice	1

1. = traditional home-brewed beer 2.= bottled beer

PARTICIPATION BY DISABLED PERSON

Tables 8 and 9 capture the general capacity of the index participants to participate in the household livelihood providing some estimate of the ability of these adults to work or be involved in some form of remunerative activity. Most of the disabled people in the study were adults. The whole group was composed as follows: 3 children; 4 adolescents; and 25 adults. One of the children attended a special school and the other two were cared for full-time at home. Three disabled adolescents required close supervision and the fourth was in the mainstream programme at high school. One of the adults was bedridden and two were beyond the age of retirement. Of the remaining group of 22, ten (eight women, two men) were the head of a household.

Table 8: Participation and productivity (disabled person)

PARTICIPATION & PRODUCTIVITY (Disabled)	NUMBER
Dependent in all activities	4
Able, but repertoire restricted by health condition	6
School children, abilities varied	4
Participates in household activities when well	5
Accomplishes household activities	3
Manages own household	7
Occasional employment	2
Self-employed	2

Table 9: Employment possibilities of disabled people

REASONS FOR EXCLUSION FROM EMPLOYMENT	NUMBER
1. Age (55+) "retired"	8
2. Health condition/impairment	12
3. Full time employment	0
4. Self employed	4
5. Occasional work	1

ASPIRATIONS

The ability to aspire is central to the motivation and hope of poor people. Table 10 indicates what the dreams and future goals of the households were providing some indication of the structural barriers that need to be addressed to assist participants in their desire to break out of the poverty cycle.

Table 10: Aspirations: head of household

ASPIRATIONS FOR THE FUTURE	NUMBER
Start/build own business	3
Get a permanent job	4
Acquire a proper house	8
Build a house for children to live in	2
Belong to the gardening club at church	1
Get son into a training centre	1
See children succeed and behave properly	4
See children succeed and care for disabled sibling	1
Pay school fees	2
Study/do something useful	1
Add rooms onto the house	2
Help child to matriculate	2
Get treatment that will cure health problem	3

NB: Some people, when they thought about the question, mentioned more than one thing.

Considering that householders did not generally venture far from their homes (going only to the local clinic, shops, close neighbours), their lives were confined within the bounds of their dwelling, limiting the range and variety of occupations that they could experience and aspire to.

SUMMARY OF FOCUS GROUPS FINDINGS

Table 11 captures key responses to the questions posed to Phase 1 participants. It provides an overview of their experiences and perspectives on questions that arose for the researchers from the demographic survey. These findings are discussed in greater detail in Watson (2005) and will not be addressed here.

Table 11: Focus groups findings

Question	Responses
1. How do you manage to live on your income? How do you and other people like you cope?	• "This year there is no money it is less than last year." Poor employment prospects make life very difficult for families, particularly as more and more people are out of work • "The family eats all the money. When I sold chicken pieces it [the money] was not enough." People try to make money through their own small business but starting out and keeping afloat is very difficult • "The money [grant] is not enough for the family" The necessity of earning some additional income was emphasised; householders said they could not manage on the grant money alone.
2. Why should a disabled person receive a grant?	• "A child depends on his mother. He cannot do things alone. I have to wash under his arms when he is smelling bad. Who else would do that?" People understood the intention of the CDG. • "The person that looks after the one that has disability cannot work." The grant is intended for a person who cannot do everything for themselves or has particular needs, like going to see a doctor regularly. • "The government is helping them to feel that they are doing something for themselves and for the family. He feels that he can contribute, can stand alone. They have self respect." Participants emphasised that not everyone is the same. • "Some can care for themselves while others cannot. People that need help should also feel that they belong [to society]."
3. Women head most of the homes that we have visited. Where are the men?	It was evident that many of the participants did not want to share their lives with a partner. • "They are there but they are useless. Therefore the women act as mother and father." The conversation led on to talk about homes where there was a disabled person, particularly a disabled child. • "Fathers leave home; they run away from a disabled child and from problems; they say that the child is not theirs. They say that problems like this do not come from their family." One mother made this poignant comment about her adult son and his father: • I have the pain of Siphiwe. The father runs away from the disabled child because he is ashamed."

4. Will your situation improve in the future and if so what will change?	The groups found this question difficult and seemed to think that there was no hope of their situation changing in the future. They seemed fearful of what might happen to them and their families in the future. Some of them offered advice: • "Pray and accept that things can change." • "Be positive. Don' let negative things stick in your mind. Try to imagine that the picture could be different." It seemed that they felt thwarted in their efforts to bring about improvements. Their comments revolved around issues of employment and income generation. • "If I could sell sausages I could sell all week. The washing of intestines makes my hands pain and it is too much water. I would rather sell sausages." • "It hurts to see my son sitting around. I hope that he will find some work, even a little." The willingness to wok was also expressed: • "If I was well again I would like to go back to being a char." And the suggested solution? • "When the children are working then it will be better."
Questions	Responses
5. Why is television popular?	Everyone wanted to have a say about this question. Not all the comments were positive, with complaints about TV being bad for the eyes, the brain cells and stopping people from reading books. The majority opinion was a justification of the position and importance that TV holds. • "It helps to know what is happening in other places. I watch the news. I want to know what is happening in the world; and • People rely on it to keep up with the world. We can learn from different cultures; and • TV is believable and it broadens your imagination. Fewer people rely on books nowadays; and • It's good for the children to learn English. They do not speak but they understand." Some people had personal reasons for watching TV. • "It is good to watch to relieve stress; and • My child sees other disabled children on the television. He knows that there are other people like him." Others had their own rules: • "I don't watch Days (Days of our lives) and Bold (The Bold and theBeautiful) because then the children will think that it is the way to behave."

CONCLUSION

This appendix presented, in broad brush strokes, the background demographics of the Phase 1 and by inclusion, the Phase 2 study sample. It demonstrates the deprivations, assets, functionings and capabilities of participants that enabled purposeful sampling for Phase 2 to occur.

APPENDIX 5: PHASE 1 PDO STUDY DEMOGRAPHIC SURVEY GUIDE AND INTERVIEW GUIDE

HOUSEHOLD INFORMATION: CHRONIC POVERTY AND DISABILITY

Recorded by:	Date:
Procedure: Introduce self Explain purpose of visit Identify head of household (h of h) Request cooperation with answering eligibility questions Establish eligibility for inclusion: ▪ Size of household: at least three people, one of whom is a disable person ▪ Income: Less than R490 per month for every adult or adult equivalent (two children under 15) ▪ Duration of poverty: More than three years ▪ Capability: free to be and do the things that the person wants to Explain confidentiality and anonymity Ask for permission to interview or if h of h is not present arrange to meet at another time Ask for permission to record interview Part 1: Questions about members of the household Part 11: Questions about household facilities Part 111: Questions about household activities. Part 1V: Questions about disabled person Part V: Questions about closest family member Part V1: General	Comments:

CHRONIC POVERTY, DISABILITY AND OCCUPATION STUDY HOUSEHOLD INFORMATION

NAME:	ADDRESS:	DATE:

PART 1: Questions about members of the household. 'h of h' = head of household

1. Name of h of h 2. Name of disabled person 3. Name of closest [1] to disabled person. NB Full names	4. How old is each of these people?	5. How many people are there in the household? i) Always ii) Sometimes	6. What is the relationship between members of the household? (record number in appropriate space)	7. How long have you lived in this place? i) Less than 1year ii) 1-5 years 111) More than 5years	8. What languages do you speak? i) Xhosa ii) English iii) Afrikaans 1v) Other (choose 1 or more)	9. Education I) None ii) Still at school iii) Junior school –yrs? v) Other give detail see below
i)	i)	i)	Mother/father	i)	H of H	H of H
ii)	ii)	ii)	Spouse/Partner	ii)	Disabled person	Disabled person
iii)	iii)	Comment: reasons for absences?	H of H Children Other Children	iii)	Person closest to disabled person	Person closest to disabled person
Relationship between h of h and D Person?			Grandchildren			Other – add detail here
			Other blood relationships – eg. Sister; uncle			
			Others – not relations			

Closest = the person most familiar with the needs of the disabled person; the one that acts when help or support is needed.

Part 11: Questions about household facilities

1. What materials were used to make your dwelling? (Tick one or more) Indicate for walls and roof	2. Is your home: i)Wind/waterproof ii) Hot/Cold iii) Fireproof iv) Is security a problem? (Answer 'yes' or 'no' for each Q)	3. Do you have access to: i) Water (where)? ii) Electricity iii) Toilet (where) (Answer 'yes' or 'no' for each Q)	4. How much space do you have? i) How many rooms do you have ii) How many are used for sleeping? iii) Is space or access a problem?	5. What type of fuel do you use for cooking? i) Wood ii) Paraffin iii) Electricity iv) Other
i) Zinc	i)	i)	i)	i)
ii) Stone	ii)	ii)	ii)	ii)
iii) Blocks	iii)	iii)	iii)	iii)
iv) Mud	iv)	Is toilet accessible for D person (add comment)?	Comment?	iv)
v) Wood	v)	v)	v)	v)
vi) Plastic	vi)	vi)	vi)	Name of other types of fuel:
vii) Other	vii)	vii)	vii)	vii)

PART 111: Questions about household activities

Activities	**Who does the following?**	**Comment**
Shopping; getting food		How and where?
Cook for the household		Where and how?
Clean dwelling and surroundings; do washing		
Childcare		Own child/grandchild; other children
Who uses transport?		What; why; where to?
Go out to work; go to look for work		What; where; when
Work at home (for money or pay in kind) or undertake some productive activity e.g. gardening, sewing		Who ; what
Does household participate in community activities e.g. choir, soccer, church, burial society, watch sport, savings group		Who, what, where, how often
What services do household members use, e.g. health, healer, education, social development, home affairs, other e.g. labour		How often, how satisfactory
Other activities not named e.g. collect wood; help neighbours; attend celebrations and ceremonies		What, why?
What are the interviewee's wishes or aspirations?		Describe

PART IV: Questions about the disabled person

Health What does the person complain of?	**Special Needs** e.g. Chair, assistive device, constant supervision	**Does the person receive a grant (social or other)**	**What tasks does the person do for more than one hour daily? Please describe**
Physical problems	Related to physical problems	Yes…… No…….	Own self care e.g. hygiene, dressing, eating
Mental Health problems	Related to mental health problems	If yes which one? i) CDG…… ii) DG…… iii) OAP…… iv) Other……	Housework/tasks in and around the home
Duration of health condition or impairment (yrs)	Has the need been satisfactory met?	If no, why not?	Attend school or training centre
Any current complaints?			Fetch water/wood; run errands

Health What does the person complain of?	**Special needs** e.g. Chair, assistive device, constant supervision	Does the person receive a grant (social or other)	What tasks doe the person do for more than one hour daily? Please describe
			Look for work
			Self employed

PART V: Questions about the family member who is closest to the disabled person

How would you describe the relationship between this person and the disabled member of the household?

What do they do together?

PART VI: General

Discuss

How special expenses are covered e.g. school uniforms, an initiation ceremony?

How is money raised for special purchases made e.g. fridge. TV, cell phone?

Does the household have debt? (if so, what). Which members of the family lend or borrow money?

What do you do when unexpected things happen e.g. someone gets sick; loses a job; the fridge stops working?

Take note of the following during the visit:

What assets does the household possess: name these e.g. fridge; TV; a bicycle; piece of ground.

How does the family make their money last till the end of the month?

How does the family cope with unexpected expenses e.g. illness of one of the members of the household; dispute with a neighbour; part of the dwelling collapses

APPENDIX 6: PHASE 2 PDO STUDY: INTERVIEW GUIDELINES

Start all interviews following acceptable cultural social processes. Build communal horizon of understanding. Reaffirm purpose, process, ethics, boundaries, time frame, tape recording, informed consent etc. Answer questions.

INTERVIEWS ROUND 1

[Index person/HOH: history of index person as occupational being]

1. Confirm household structure from Phase 1 data set. Draw & clarify CURRENT genogram
2. Shift to childhood: commence with occupational storytelling. Where born, raised, schooled etc but stay focussed on what s/he DID, i.e. tasks, chores & responsibilities for efficiency of household, participation in economic activities of the household, play activities, play objects, playmates, what occupational skills/knowledge learnt from elders … probe for insights into the OCCUPATIONAL BEING making links where indicated with livelihoods, basic needs, human needs, freedoms. Draw diagrams.
3. PROBE across age bands (under ten between ten-15; 15-20, 20-30 etc): values, meanings, purposes of identified critical occupation(s), roles & responsibilities in household; gender, cultural patterns in occupational choices; how was TIME used and organised around eg. productivity, social, cultural, political activities
4. Employment history: where, job done, why left, what skills acquired,
5. Current time use: typical day, week, month, year (e.g. rural-peri-urban trips).

INTERVIEWS ROUND 2

[index person/HOH: living with a psychiatric disability]

1. History of mental illness: when, where, how, what, why, who
2. Describe your typical day. Typical week. What did/does your illness do to your ability to do the things you want and need to do everyday? Probe for functional limitations, strengths, needs. Use COPM format
3. In which ways does your mental illness affect your welfare/well-being (financial, social, spiritual, psychological etc)? That of your household?
4. How does society (probe: your social circle, people in the community, employers, friends, family); (probe: the economy, politics, public services etc) affect your mental health and functioning?
5. What was your hospitalisation /clinic visit experience(s) like? What was/is helpful?

What would you change?

INTERVIEWS ROUND 3

[index person/HOH: living in poverty]

1. What does being poor mean to you? To your household? To society?
2. What do you think poverty does to your illness and what does your illness do to poverty?
3. If you could change your circumstances what would you want most of all? What do you aspire to?
4. What things have poverty and being mentally ill taught you? What lessons/advice or what can you teach the government, us (researchers) or health service providers about living with a mental illness and living in poverty?
5. What does getting a disability grant mean to you? How do you use your grant? What impact does the grant have on the household? Who decides?

INTERVIEWS ROUND 4

[index person/HOH: key livelihood occupation]

1. Can you tell us the story of (the occupation). When did you start doing it? How was the occupation created and learned? Why did you start doing this occupation?
2. TASK: I do not know anything about doing this occupation. Can you please teach me the occupation? Describe what its tasks and activities, tools, materials, procedures etc are.
3. When, for how long, why do you do this occupation? Probe for macro/ micro sociocultural and personal influences e.g. health status, debt, seasonal changes,
4. Who do you do this occupation with or for? Why?
5. What other things do you do related to this occupation for example budget, plan, delegate, control
6. SITUATION: characteristics of place where occupation is performed, what helps or hinders e.g. access to running water needed
7. What helps/hinders you in this 'doing' location of the occupation?
8. Who else is involved, do they help/hinder? Why?
9. What pressures (e.g. health related, social) do you experience doing this occupation/ tasks in it etc?
10. What is the meaning/purpose (values/attitudes) of doing this occupation for you? What would help you increase the economic gains from this occupation?

11. DOER: what things do you do well and know a lot about? What things are hard for you? In what way does you health influence you ability to function in this occupation?
12. What's in it for you and your household? Why this income generating occupation and not something else? Can you describe the contribution that this occupation has made to you as a person, to your household, to your community?

INTERVIEWS ROUND 5

[HOH: costs of mental illness & strategies to deal with poverty and psychiatric disability]

1. Roughly how much does your household spend on overall welfare of index person per week (smoking, transport to health care facilities etc)?
2. In which, if any, ways has your household suffered costs due to damages caused by index person either in the home or to other people's property? What are the consequences of these damages?
3. Has the household acquired any debt due to the illness and if so how? How much? How will/do you repay this?
4. How does the household deal with money shortage created by having to meet the treatment and other needs of the index person?
5. What, in your opinion, has the impact of the index person's illness and illness behaviour been on the household?
6. What has your household done to manage the impact of the index person's needs (economic and otherwise) and behaviour on the household?
7. What are the most difficult economic burdens for your household when a member is mentally ill?
8. In which ways have the mental health and other public services helped or not helped this household?
9. In which ways have traditional health services helped or not helped this household?
10. What, in your opinion, does the disability grant mean to or do for the index person? The household?
11. Identify things you think the government should do differently or better to help households like yours who have a member who is mentally ill.

FOCUS GROUP QUESTIONS

Three main questions:

1) What are your needs?
2) How do you meet these needs? WHY do you choose to do this?
3) If you don't meet your needs what do you do to get around this? Why do you choose to do this?
4) What are the livelihood strategies that enable survival?

APPENDIX 7: AUDIT TRAIL

STEP 1: TRANSLATION & TRANSCRIPTION OF RAW DATA
STEP 2: CONDENSATION THROUGH READINGS OF TEXT (clarify core emerging ideas in relation to research questions) & MANUAL CODING LAYER 1 [codes addressing research questions]

Red: what are the personal, environmental and occupational assets/limitations?

Green: how is occupation created, learned, shared?

Brown: how is occupational performance affected by location/context?

Blue: what patterns of occupation /habits are evident in lifestyle & health behaviours? Do they impede/facilitate livelihood?

Orange: what potential exists for doing occupation? Abilities? Evidence of agency?

Purple: what meanings/value/purpose is ascribed to occupation?

STEP 1: TRANSLATION & TRANSCRIPTION OF RAW DATA

Example: Ref D3.9

I: Now where does the selling happen here in Khayelitsha? Do you have only one street corner to sell or any other selling spot?

R[D]: Yes, only one. The one you found me at the other day. We used to sell in Site C at the Taxi Rank but more and more taxis are joining the rank and it became too full around the spot where we were stationed. Now we are just selling here at this street corner.

I: So you started off by selling in Site C Taxi Rank?

R[D]: Yes.

I: What made you to decide going to Site C the first time around?

R[D]: That was the only place to do business in at the time but now it became too full.

I: And now if it's full what hinders you from continuing with your business?

R[D]: If it's full it means there are a lot of other people that are selling clothes as well. There is too much competition for me then.

I: So that is how you do this business, you just sit there at the corner and wait for people to come by your spot? Have you not considered going door-to-door to sell these clothes?

R[C]: We do that sometimes when it's raining because you cannot lay out the clothes when it's raining and the wind also distracts our setup. So I take the bags and go house-by-house selling the clothes. Sometimes you get something, sometimes you get nothing.

R[I]: Are you the only one going to the different houses or does D also accompany you?

R[C]: I go alone. She would be unable to endure the work if she had to do it with me because she is not very healthy as I said. But sometimes she takes the chances and I allow her to but somewhere along the way she gets tired and I send her back home.

R[D]: My worst problem with the houses is that they do not want to pay. They have never beaten me up before but they become cheeky with my money. To avoid fighting with them I decided that I will never go to the houses again. I'd rather sit at my street corner and sell my clothes there. Sometimes they wear it and wear it and wear it and when I go to collect my money, I see them bringing it back with no explanation.

STEP 3: DEDUCTIVE SUBCATEGORISATION PER RESEARCH QUESTION & NOTING PATTERNS (rephrasing & compressing into meaning units)

EXAMPLE: What are the personal, environmental and occupational limitations or assets of index person/household?

personal	environmental	occupational	comments
I was mentally disturbed, taking off my clothes, beat people and I also did not eat for a whole week *I used to take water only (D12)* *I get injection but if I forget my date I will have a terrible headache (D12).* *I don't write down I keep them (creditors) on my mind because I can't write my hands are shaking (D12)* *I don't forget. I even know the amounts by head. Sometimes they give me half of the amount, I even keep that on mind. I can't write them down (D13)*	*I go to my brothers when I have a problem (D12)* *They (brothers) are supporting me* *I get it (meds) here at site B* *She does not even pay school fees for her child (D14)* *She takes her bank card to the shop owners to do some groceries. They take all her money and give her R7 change (D14).* *I stay happy with my neighbours (D15).* *This place is always on fire especially during December and Easters (D15).* *My community support me to survive in life (D15).*	*I was given this child by my family since I cannot wash my clothes so she is doing my washing and I am educating her (D15).* *She (girlchild) does shopping for me to do some groceries for me (D15)* *Elements:* *Actors* ✓ *Rules* ✓ *Resources*✓ *Conventions* ✓	severity of psychotic episode: [impairment] Recognises role of meds in health [access]; what happens to productivity when she gets head-aches? Impact of impairment: shaky hands means she has to rely on memory to ensure she recoups & settles debts [adaptation] reliance on brothers & neighbours; senses community support; [Relational economy]:distrust of certain shop owners; risk of fire [structural] ? functions of childcare: [form of exchange] [adaptive strategy] [exploit child?]

STEP 4: CONDENSATION THROUGH RE-READING OF TEXT (clarify core emerging ideas) & MANUAL CODING AND SUBCATEGORISATION LAYER 2 [codes addressing three core constructs: occupation, disability, poverty]

EXAMPLE: DISABILITY RELATED CODES

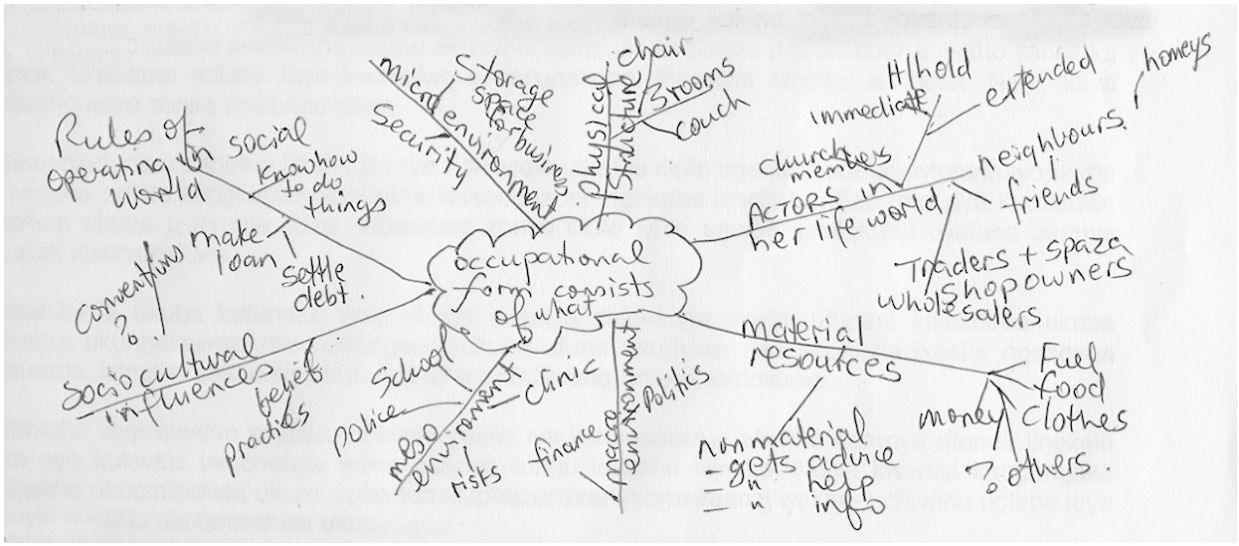
DISABILITY	COMMENT
Yes I see myself as a disabled person in a community in general (D24) *By being mentally disturbed…even if I go to the tap to get some water little children make fun of me (D24)* *My neighbours treat me like a fool or can I say 'rakie' a mentally disturbed person who cannot even help out her neighbours provide if she has to (D25)*	*What does she mean by 'disabled"? by'community? Is this intellectual insight?* *Does she apply it in making sense of her experiences? Why do children mock her? Did they see or hear about her psychotic episodes? What does 'rakie' mean?* *Contradiction: she feels supported by community, says that she stays happy with them yet feels as if they treat her like a fool. Meaning of text in context of conversation: she links her inability to help her neighbours (reciprocity of cash or kind) to her mental illness and not to her poverty*

STEP 5: CONDENSATION THROUGH RE-READING OF TEXT (clarify core emerging ideas) & MANUAL CODING AND SUBCATEGORISATION LAYER 3 [codes addressing the basics of occupation: OF, DS, M&P, OP]

EXAMPLE: M&P

MEANING & PURPOSE	COMMENT
My money is being handled with care because there is no man that I am staying with who wants my money (D11) *I don't like to ask from other homes (D11)* *It (getting a grant) encourages me (D13).* *I don't like it (prostitution) because she will teach my children what I am not doing (D14)* *We work together (D14)* *You can say that Madlomo is a friend indeed* *We discuss how to survive in life, we also discuss if how to raise our children (D14).* *sometimes it just happens to see a person entering my house to give me some second hand clothes that I can sell. So usually I say that those are the work of god (D15).*	*Inference about gender? patriarchy? Sense of pride in economic self sufficiency? Has reservations about dependency, motivated to do things for herself, DG provides some emotional support; has clearly defined moral principles, motivated to act because of partnership & friendship; finds support in discussing critical life issues; attributes financial windfall to the intervention of God;* *Meaning of text in context of conversation: she appears to find some meaning in her relationship with M; in her beliefs and morals and in being able to manage her own affairs*

STEP 6: CATEGORISATION: multiple mindmaps creating coherent patterns; identifying elements in basics of occupation; building a logical chain of meaningful events or critical speculations



STEP 7: NARRATIVE STRUCTURING & THEMATIC INTERPRETATION: creating conceptual/theoretical coherence; identifying points of learning, making assertions

EXAMPLE: [OF]

ELEMENTS IN THEMATIC SUB-CATEGORIES: What elements of OF impacted on OP?	Actors: immediate & extended h/h members, 'homeys neighbours, business partner, spaza shop owners, 'vambos', traders, wholesalers, loan sharks, burial society, church friends, clinic sisters Rules: payment in cash or kind (clothes, fuel, food, help); loan in cash or kind; fee for service; ascribe intentions ETC
THEMATIC SUB-CATEGORIES: What categories of OF existed in the data?	Social interactions with actors : supportive or undermining Exchanges using rules: outward & inward ETC
THEMATIC CATEGORIES: How was OF structured to elicit relatively predictable OP?	a circuit of supportive and undermining social connections a web of giving and receiving transactions ETC
THEMATIC DESCRIPTOR: What was Dorcas's unified response to OF?	"...the community supports me to survive by life..." "...sorting things out with the DG..." "...they take advantage that I am a mentally ill person..." "...some people can be very cruel..." " ...finding a good way to do business..." ETC
THEME: Core feature of OF	EMERGES FROM INTEGRATED AND COMPLETED PICTURE OF THE ABOVE SECTIONS

The various steps described above follow one participant through the analysis process. The menu of categories is not emic so other configurations are possible.

APPENDIX 8a: PHASE 2 PDO STUDY: INFORMED CONSENT

UNIVERSITY OF CAPE TOWN

Molo ……..

IPROJEKTHI YOPHANDO

Ndilandela isifundo sikaNjing Ruth Watson apho wena ubuthabathe inxaxheba ngonyaka ka2004.

NjengoNjing Watson, ndiyi occupational therapist, ndifuna ukufunda ngamava abantu abahlala nabantu abahluphekileyo nabanelungu losapho elikhubazekileyo.

Ndifuna ukwenza udliwano-ndlebe nabafazi abafana nawe ukuze ndazi ngcono izinto ozenzayo (imisebenzi) yemihla ngemihla. Ndiyakholwa ukuba oku kuya kundinceda (ekuhambeni kwexesha nabanye) ekwazini ukuba uhlala njani neemeko zakho kunye nezinye iinzima ozifumanayo.

Ukuba uyavuma ukuthatha inxaxheba, ndiya kufuna ukudibana nawe ubuncinane amathuba amane ukuya kutsho kwamathandathu ekhayeni lakho ukuze sixoxe ngemisebenzi yakho yantsuku zonke. Udliwano ndlebe luya kwenziwa yi-occupational therapist ethetha isiXhosa. Nam ndiya kubakho kuzo zonke iindibano nawe.

Ndisenokufuna ukuthatha iifoto (okanye ndikucele uthathe iifoto ngekhamera endiyiphetheyo) kuba le yeyona ndlela ilungileyo yokuthatha imisebenzi njengokuba iqhubeka. Ezo foto ziya kuthathwa kuphela ukuba uyavuma. Uza kuboniswa zonke iifoto yaye ugqibe kwelokuba uyafuna okanye akufuni zisetyenziswe.

Kubalulekile ukuba kufuneka wazi ukuba awunyanzelekanga ukuba uthathe inxaxheba ukuba ukhetha ukungakwenzi oko. Ukongeza, ukuba ufuna ukurhoxa nangaliphi na ixesha ngexesha lophando, isigqibo sakho siya kuholonitshwa nodliwano-ndlebe lurhoxiswe.

Ndithatha isiqinisekiso sokuba imfihlelo yakho iya kukhuselwa – akukho namnye ofunda iingxelo zam oya kukwazi ukuchonga wena okanye ilungu losakho lwakho. Ndiya kwenza

kangangoko ndinakho ukuqinisekisa ukuba uphando aluphazamisani nomsebenzi wakho-udliwano ndlebe luya kwenziwa ngokokuthanda kwakho.

Ukuba kuyenzeka ukuba wena okanye ilungu losapho lwakho alikhululekanga nangaliphi na ixesha, ndiya kufuna kubonakaliswe oku. Ukuba wena okanye ilungu losapho lwakho liziva ukuba nangaliphi na ixesha uphando kufuneka luyekwe, ndiya kuyithobela loo nto. Usenokudibana nomqeqeshi wam kwiYunivesithi yasekapa – UNjingalwazi Lana van Niekerk – kwinombolo ……. ukuxoxa ngezinto ofuna ukuzazi. Ndifuna nokukwazisa ukuba, njengelungu lomsebenzi wezempilo, ndinyanzelekile ngokusemthethweni ukuba ndixele kwabasemagunyeni nayiphi na imeko yokuphathwa gadalala kwabantwana okanye ukuphathwa gadalala kwabantu abakhubazekileyo endikubonayo. Ndiya kukuqinisekisa ukuba, ukuba loo nto iyenzeka, ndiya kukwazisa ngeentshukumo zam. Akukho nto iya kwenzeka ungaziswanga.

Ndineenjongo zokufumana iPhD kolu phando. Kuya kubakho ingxelo eya kuthi ifumaneke ekupheleni kolu phando kwabo banomdla wokufunda. Kuya kwenziwa amaxwebhu abhaliweyo ngexesha lophando. Akusayi kusetyenziswa maphepha-ndaba, zincwadi okanye oomabonakude ekuxoxeni okufunyanwe kolu phando. Ndiya kukukhuthaza ukuba ufunde iingxelo zam ngendikubonileyo nendikufundileyo, yaye ndiya kuzamkela nazipphi na iingcebiso onazo. Njengokuba senditshilo, igama lakho alisayi kusetyenziswa nakweyiphi na ingxelo.

Andikwazi ukuba ndingakunika intlawulo eninzi ngenxaxheba oyithathileyo. Ukuba kukho nto endiyifumanayo apho kunokuzuza wena okanye ilungu losapho lwakho, ndiya kukwazisa. Ndiya kukunika kananjalo isidlo (esifana nesiya sikhutshwa nguNjingalwazi Ruth Watson) kuhlelo ngalunye lodliwano – ndlebe.

Ndiyithobela kakhulu imvume endiyinikiweyo. Ukuba uvuma ukuthatha inxaxheba kuphando lwam, ikho ifomu yemvume ekufuneka ifundiwe yaza yasayinwa.

Ukuba kukho imibuzo ofuna ukuyibuza ngokuphathelele kolu phando, ungandifumana kwezi nombolo zilandelayo: 021…….okanye 083 ……

Enkosi. Ngemibuliso!

Madeleine Duncan (Nksk)

APPENDIX 8B: PHASE 2 PDO STUDY INFORMED CONSENT

UNIVERSITY OF CAPE TOWN

Dear ……..

RESEARCH PROJECT

I am following up on the study of Prof Ruth Watson in which you participated during the course of 2004. Like Prof Watson, I am an occupational therapist, wanting to learn from the experience of people who have to cope with being poor and who have a disabled family member.

I wish to conduct interviews with persons like yourself in order to better understand the things that you do (activities) every day. I believe that this will help me (and later others) to understand how you cope with your circumstances and some of the hardships that you experience.

Should you agree to participate, I will want to meet with you on at least four but up to six occasions at your home to discuss your daily activities with you. The interviews will be conducted by a Xhosa-speaking occupational therapist. I will however be present at all meetings with you.

I may wish to take photographs (or ask you to take photographs with a camera that I will provide) as this is a good way of capturing activities as they happen. Such photographs will however only be taken if you are in agreement. You will be shown all the photographs and can decide whether or not they may be used.

It is important that you should know that you are under no obligation to participate should you prefer not to do so. In addition, should you wish to withdraw at any stage during the course of the research, your wish will be respected and the interviews will be terminated.

I undertake to ensure that your confidentiality will be protected – no-one reading reports on my research will be able to identify you or any member of your family because I will use

different names. I will also do my best to ensure the research does not disrupt your routine – interviews will take place at your convenience.

If it so happens that you or any member of your household is uncomfortable at any point, I would welcome an indication of this. If you or any family member feels at any stage that the research should not continue, I will comply. Alternatively, you may contact my director at the University of Cape Town – Associate Professor Lana van Niekerk – on.. …… to discuss any concerns you may have. I also need to inform you that, as a member of a health profession, I am obliged by law to report to the authorities any instance of child abuse or abuse of a disabled person that I may observe. I would like to assure you that, should such an unfortunate instance occur, I will inform you of my actions. Nothing will happen without you being notified.

I hope to obtain a PhD from this research. There will be a report at the end of the research process that will be available for interested persons to read. Journal articles may be produced during the research process. It is not envisaged that newspapers, magazines or television will be used to communicate findings from this research. I will encourage you to read my accounts on what I have observed and learnt, and will welcome any comments you may have. As I have said, your name will not be used in any report.

I am not able to offer much in the way of compensation to you for your valued participation. Obviously if I am aware of any resource from which you or any member of the household might benefit, I will inform you accordingly. I will also provide a small thank you by way of a food parcel at each interview session.

I regard the permission that may be granted, highly. Should you agree to participate in my research, there is a consent form to read and sign.

If there are questions that you wish to ask regarding this research, you can reach me on the following numbers: …….

Thank you. Greetings!

Madeleine Duncan (Mrs)

APPENDIX 7B: CONSENT FORM

UNIVERSITY OF CAPE TOWN

IFOMU YEMVUME

Ngokusayina ngezantsi, mna……. ndinika imvume uMADELEINE DUNCAN, weYunivesithi yaseKapa, ukuba andityelele ukuze enze uphando ngemisebenzi yam yantsuko zonke. Imibuzo iya kuquka indlela endilisebenzisa ngayo ixesha lam, ukuba ndiphila njani nezinto ezingonelanga yaye iyintoni indima yam ekujongeni ilungu losapho lwam elikhubazekileyo. Ndyiqondile injongo yophando. Kuvunyelwene ukuba, ukuba nangaliphi na ixesha ndifuna ukurhoxa kuphando, oku kuya kuhlonitshwa yaye nokubandakanyeka kwam kuphando kuya kupheliswa.

Igama: ……..

Umsayino : ……..

Usuku: ……

CONSENT FORM

In signing below, I …….grant permission for MADELEINE DUNCAN, of the University of Cape Town, to visit me in order to conduct research on the activities that form part of my everyday life. Questions will explore how I use my time, how I cope with being having restricted resources and what my role is in caring for my family member who is mentally ill and/or disabled. I understand the purpose and aims of the research. It is also agreed that, if at any point I wish to withdraw from the research process, this wish will be respected and my involvement in the research will be terminated.

Name : ……..

Signature : ……..

Date : ……

APPENDIX 9: CROSS CASE GENERALISATION OF CORE ELEMENTS IN BASICS OF INCOME GENERATING OCCUPATIONS

ELEMENTS	DORCAS Selling 2nd hand clothes	VUZI Casual vendor assistant	SESETU Cardboard collection & selling	SIYANDA Entering competitions	FUZILE "Being disabled" (provider of a DG)
OCCUPATIONAL FORM	Actors Rules of exchange Topography Social conventions Civic structures Material resources Non-material resources	Actors Rules of exchange Topography Social conventions Civic structures Material Resources Non-material resources	Actors Rules of exchange Topography Social conventions Civic structures Material resources Non-material resources	Actors Social conventions Civic structures Material resources Non-material resources	Actors Social conventions Civic structures
DEVELOPMENTAL STRUCTURE	Delegation Relocation Diversification Compensation Accommodation Isolation Encapsulation Modification Valuation	Delegation Compensation Accommodation Encapsulation Modification Valuation	Delegation Diversification Compensation Accommodation Modification Valuation	Accommodation Isolation Encapsulation Modification Valuation	Accommodation Isolation Encapsulation Valuation
MEANING & PURPOSE	Signification Resignation Expectation Goal orientation	Signification Resignation Expectation Goal orientation	Signification Resignation Expectation Goal orientation	Signification Resignation Expectation Goal orientation	Signification Resignation Expectation Goal orientation
OCCUPATIONAL PERFORMANCE	Choring Sourcing Transporting Storing Preparing Valuing Displaying Trading Cash handling Restoring Relating	Choring Sourcing Transporting Storing Preparing Valuing Displaying Trading Cash handling Relating	Choring Sourcing Transporting Storing Preparing Valuing Trading Cash handling Relating	Choring Sourcing Preparing Valuing Relating	Choring Relating

Picture 5: selling second hand clothes

Picture 6: casual fruit and vegetable vendor assistant

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