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The occupational dimensions of poverty and disability

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Abstract

This paper is based on ongoing research into the form, performance and meaning of all the things that particularly vulnerable people do every day i.e. their occupations¹. Occupations are the building blocks for livelihood². The relationship between occupation, poverty and disability is explored through the case study of a household with two adult disabled members living in a remote rural village in the Eastern Cape Province, South Africa. The description of their many deprivations illustrates how a scarcity of opportunities, resources and supportive infrastructures influences human development, agency and functioning and is compounded by disability. The concept of occupational poverty depicts the marginalisation of disabled people and their households. A community based rehabilitation approach is recommended as a means for promoting the inclusion and participation of disabled people, their households and the community in development initiatives, through the facilitation of each person's occupational performance.

Ayanda Tole³, aged 44⁴, is a profoundly deaf, unemployed Xhosa man who lives in a small village in the rural Eastern Cape Province (South Africa). Cycles of misfortune have not overwhelmed Ayanda and his wife Noshile despite the many challenges that they face daily in building a life for

¹ Occupation is not the same concept as livelihood; the former is associated with discreet tasks and activities executed within chunks of time, aligned with cultural role expectations, and done for particular purposes, to capacitate and enable human performance,

² Livelihood comprises capabilities, assets (natural, physical, human, financial and social) and activities 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).

³ All registers that might lead to identification of the study participants have been removed

⁴ His age in 2007

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themselves, their three young children and an uncle who has a long history of mental illness. The Tole household serves as a case study to foreground occupation; that is, everything that they do every day, the ways that they spend their time and energy and ultimately on how this influences their welfare. The emphasis is on the relationship of occupation to human development, personal wellbeing and health in the context of chronic poverty⁵. Applying an occupational lens⁶ to the relationship between poverty and disability reveals the barriers and facilitators that operate at a nano level in disabled peoples⁷ lives including their agency, abilities and aspirations. We argue that disabled people are 'doing beings,'⁸ worthy and capable of inclusion and participation in any poverty reduction initiatives. Their participation must start with an appreciation of their right and the potential to determine their own future provided certain preconditions exist including the supportive facilitation of their occupational performance in context⁹. The term 'occupation' as it is used here encompasses more than work or employment. It includes "all that people need, want, or are obliged to do including what it means to them and its ever present potential as an agent of change" (Wilcock, 2006:9). Occupation is by its nature complex, difficult to understand and challenging to capture. It has dimensions related to performance including the interests, abilities and skills of the doer to make use of the tools, materials and/or opportunities at his or her disposal. The different dimensions of occupation are related to where and when it is done and under what structural circumstances. It also involves personal,

⁵ Chronic poverty is severe, multi dimensional, intergenerational and of long duration, as defined by Hulme, Moore & Shepherd (2001)

⁶ Using an occupational lens involves looking at and thinking about people as actors in their lived environments.

⁷ The term 'disabled people' is used as opposed to 'people with disabilities' as the former is preferred by Disabled People South Africa (DPSA)

⁸ 'Doing' refers to actual engagement experienced as embodied action or mindful activity unfolding over time. 'Being' denotes experiencing our existence, nature and constitution through the things we do and thereby becoming renewed or diminished (Hocking, 2000)

⁹ We do not presume to speak on behalf of disabled people. Our aim is to foreground a teleological way of looking at and thinking about the development of humans as actors in their world

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social, cultural and historical meaning. Despite its complexity, occupation is “so much part of everyday life that it is reasonable to make empirical statements about it” (Wilcock, 2006:9). What people do (or not) can be observed and described, providing objective and subjective evidence of their participation in daily life. While disability¹⁰ is a political issue associated with the exclusion and marginalisation of disabled people from mainstream socioeconomic development, it is also a personal experience; affecting people who have an impairment¹¹ and their households in unique ways. We believe that the dynamics of disability must be addressed at both levels for sustainable development to occur and therefore focus on the latter in this paper (Watson & Swartz, 2004).

In the first section we clarify the theoretical and research background to the paper. We then address occupation in greater depth, highlighting the features of occupational poverty and agency with which disabled people and their households approach the challenges facing them. We use a single case study of the Tole household in the second part of the paper to illustrate some of the issues raised in the first part. The final section addresses the relationship between poverty, disability and occupation (PDO) making the case for community based rehabilitation (CBR)¹² as a comprehensive multi-sectoral strategy to facilitate participants’ occupational performance. CBR enjoys international support (see footnote), is designed to be inclusive, is

¹⁰ Disability is defined as a form of social inequality or disadvantage resulting from oppressive social structures and processes rather than from individual difference or biology (Priestley, 2006: 23)

¹¹ Impairment refers to a limitation in a body structure or function (World Health Organization, 2001a)

¹² Community based rehabilitation (CBR) is a strategy within general community development for the rehabilitation, equalisation of opportunities and social inclusion of all children and adults with disabilities. CBR is implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education, vocational and social services. The major objective of CBR is to ensure that disabled people are empowered to maximise their physical and mental abilities, have access to regular services and opportunities and become active, contributing members of their communities and their societies. (Joint position paper of the International Labour Organisation (ILO), United Nations Educational, Scientific and Cultural Organisation (UNESCO), United Nations Children’s Fund (UNICEF) and World Health Organisation (WHO), 2002)

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poverty reduction and community development orientated and has a medical component which includes rehabilitation.

Theoretical background

An occupation centred understanding of human behaviour is foundational to the academic and professional disciplines of occupational science¹³ and occupational therapy¹⁴. Both these disciplines have moved beyond the narrow medicalisation of disability towards a broader appreciation of humans as occupational beings. Grounded in the biomedical and social sciences, they subscribe to normative interpretations about the links between what people do, their health and well being and their development (Wilcock, 2006; Molineux, 2004; Larson, Wood & Clark, 2003). The study of occupation focuses on how people throughout the life span use their time, energies and interests to reflect and influence their personhood, circumstances and development trajectories (Polatajko, 2004). Early milestones have traditionally been established by developmental theorists such as Gesell (1928) and his colleagues, who named the things children can be expected to do at different ages and stages in terms of their neuromaturational preparedness. The extent to which 'doing' reinforces and extends 'becoming' however depends on external as well as inherent forces (Davis & Polatajko, 2004:109). The environment (Bronfenbrenner, 1979) including sociocultural influences (Iwama, 2005) determines how

¹³ Occupational science is the study of humans as occupational beings (Yerxa, Clark, Frank et al, 1989)

¹⁴ Occupational therapy is a profession committed to "promoting health and well being through occupation. The primary goal of occupational therapy is to enable people to participate successfully in their activities of everyday life. Occupational therapists achieve this outcome by enabling people to do things that will enhance their ability to live meaningful lives or by modifying the environment to better support participation" (World Federation of Occupational Therapy, 2005). Therapy occurs within the context of primary health care, which encompasses health promotion, prevention, treatment and rehabilitation.

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humans are able to thrive, develop or stagnate through their occupational endeavours.

Occupation is believed to have transformative potential when opportunities, motivation and other occupational engagement essentials are activated so that the doer can learn, discover meaning, and exercise choice and control (Townsend 1997). Understanding how this plays out under different circumstances and in various life courses and places, is an ongoing quest for occupational scientists who see the study of occupation as pursuing "...the widest and deepest questions concerning human beings as actors who adapt to the challenges of their environments via the use of skill and capacities organized or categorized as occupation" (Yerxa, 1993:6). Theorists from different disciplines offer their perspectives as to what is required in order for people to fulfil their humanness for example, basic needs (De Haan, 1998), livelihood (Ellis, 2000), capability (Sen, 1999) and human scale development (Max-Neef, 1991). Important in their own right, these and other perspectives address distinctive features of humans as socioeconomic actors.

There are two reasons why an occupational perspective was adopted in this paper. Firstly a teleological stance towards human development is based on conceptions about the links between 'doing', 'being' and 'becoming'¹⁵ (Wilcock, 2006) which sets occupational therapy and occupational science apart from other approaches to human activity such as development and welfare economics. Secondly, a concern with promoting quality of life and participation in everyday activities at an individual level stands in contrast to the systemic and structural concerns and scale associated with development

¹⁵ '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 manifestation or realisation (adapted from Wilcock, 2006)

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economics. We suggest that these two perspectives offer particularly nuanced insights into the challenges of poverty and disability.

Research background

The Tole case study forms part of an ongoing, mixed method research project funded by SANPAD¹⁶, the purpose of which is to advance an understanding of adult disabled people (between the ages of 18 and 59 years old) as occupational beings in a deprived rural environment. Seventy-six households in fifteen remote rural villages in the Eastern Cape Province (South Africa) were screened for inclusion using a set of criteria related to household size, reported assets, duration of poverty, and the presence of at least one person with an impairment who experienced performance restrictions as the result of their individual and environmental context.¹⁷ Forty-four of the screened households met the inclusion criteria. The reported heads of the household and the disabled person(s) (this was sometimes the same person) were interviewed using a semi-structured questionnaire focussing on demographic and contextual information. A second substantive interview was conducted with thirty-one households yielding descriptive data about their current circumstances and occupations (Watson, 2008). Ideas presented in this paper are based on patterns of occupational behaviour evident across the cases interviewed in this particular geographical context. Phase two of the project, due to commence in January 2009, will involve prolonged engagement over the next three years with fifteen households to explore the relationship between chronic

¹⁶ South African Netherlands Partnership in Development (SANPAD) Project Number o6/18. Phase One report is available on request from the authors

¹⁷ People were included in the sample if they had a physical, sensory or psychiatric impairment

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poverty, disability and occupation using life history and case study methodologies. Anticipated outcomes of the project include qualitative descriptions of the lives of multiply disadvantaged people and recommendations for the implementation of existing policy within regional services (see figure 5).

Information for the Tole case study was collected over a period of 9 months and six visits using mixed research methods including a screening survey, observation, interviewing, iterative reflection and reflexivity, journaling and discussions between the authors and a reference group, all of whom are occupational therapists. The veracity of the research findings depended on an accurate and sensitive reading of situations and the use of professional judgment about the impairments involved, since most of the participants were not formally diagnosed and very few had received either rehabilitation from the health services or support from the disability sector. A validated picture of occupation emerges when, like a puzzle, its various elements are systematically identified, analysed and interpreted using a scientific understanding of the biopsychosocial functioning¹⁸ of the person in relation to the tasks at hand in a particular performance environment (Lamport, Coffey and Hersch, 2001). For example, an analysis of the cognitive, affective, physical and sociocultural demands of preparing a traditional meal on an open fire and an appreciation of how different health conditions may affect a persons judgement, ability to problem solve, concentrate and even hold a tool will tell the experienced observer whether or not adaptive functioning is occurring or possible. It was difficult to access nuanced data given the lack of a shared language (informants are Xhosa speaking) between the researchers and participants, our disparate backgrounds and social histories. Appropriate ethnographic research stances and ethics were adopted while

¹⁸ Biopsychosocial functioning refers to the dynamic relationship between biological, psychological and social factors in human behaviour

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skilled translators and cultural broker/interpreters provided constant feedback and offered insights in response to numerous questions. The trustworthiness of the information provided must be weighed against these limitations.

Understanding occupation

From an etymological standpoint, “parings of the words *occupation*, *activity* and *practice* have similar meanings. For example doing is one of the many meanings of ago, the derivation of activity, and ‘prasso’ the derivation of practice, ‘keeping busy’, or ‘being engaged,’ is a shared meaning of ‘occupatio’ (from Latin and Greek) (Hinojosa et. al., 2003:10). These etymological interpretations of the word suggest that occupation has a strong phenomenological component; that is, it is experiential and occurs in praxis at the interface between the person and the environment in the stream of time. As an integral part of humanness, occupation serves evolutionary, biological as well as social and economic functions (Wilcock, 2006). Since occupations may be learned (for example how to care for a baby; herding cattle, playing a game) they become the means through which people meet their needs (for example personal ablutions or building a dwelling) and give expression to their essence, abilities, interests and values (for example ‘being’ an artist, a sangoma¹⁹ or community volunteer). In a nutshell, occupations “enable us to declare our existence in the world and express our relations with others” (Christiansen and Baum, 1998:4).

¹⁹ Sangoma is a isiXhosa word referring to a traditional healer or diviner

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An occupational view of humans as actors in their various life spaces focuses not only on the tasks and activities (see Table 1) that engage their time but also on people as meaning-making beings. The *meaning* associated with an occupation can however not be assumed because this is always personal for the doer. Occupation may also be about belonging, encompassing “the importance of relationships for pleasure and the affirmation of worth” (Hammell, 2004:302), and about identification with groups that have special significance for the individual (for example belonging to a burial society or a church group). Exploring meaning inevitably leads people towards sharing the various purposes of their activities and vice versus thereby yielding important information about the personal, social and economic dimensions of their time use (Christiansen and Townsend, 2004). A number of taxonomies, frameworks and conceptual models exist for defining, classifying, analysing and facilitating human occupation (see for example Christiansen and Townsend, 2004; Kramer, Hinojosa and Royeen, 2003). Of relevance to this paper is the idea that occupation involves an integration of roles, tasks and activities; extends over time; captures people’s energy and interest; has meaning and value for the doer and can be named in the lexicon of the culture.

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Table 1 : Differentiating occupation, roles, tasks and activities

	Occupation	Role	Task	Activity
Definition	The ordinary & extraordinary things that occupy peoples time, energy, interest and attention	A culturally defined position in society	A collection of activities related to the accomplishment of a certain goal	The state of 'being active', of 'doing', of performing
Example	Gardening	Gardener	Growing a crop	Hoe, weed, plant, water, mow
Characteristics	Extends over time; has value , purpose & meaning to the doer; can be named in the lexicon of the culture; can be classified e.g. as work, play, leisure, self care	Behaviour constructed to fulfil specific responsibilities and privileges	Most tasks are assigned, selected or required, and related to the development of occupational performance skills	Unit of action that demonstrates an individual's attributes and has a particular purpose
Requirements	Infra structure, systems, opportunities	Socially accepted functions with an accepted code of norms	Knowledge, skills, time, energy, interest	Intrinsic performance components (e.g. muscle strength, stamina, judgement) Extrinsic resources (e.g. tools, seed, water)

Humans perform a range of pursuits for various purposes (for example work/play/learning, leisure and self maintenance) in a range of physical, social and cultural environments (including people, objects, resources; organisations and traditions). Their roles direct and shape occupational engagement over time, are socially sanctioned, endowed with responsibilities and status fitting to a particular cultural milieu and

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dependent on the availability of personal, social, material and structural support. Tasks, the objective for accomplishing a series of activities, are dependent on access to resources and can be improved concomitant with guidance and practice into performance skills. Activity is a circumscribed unit of action with identifiable steps and procedures that draw on a range of intrinsic performance enablers (for example cognitive, psychological, physiological, sensory and neuromotor abilities). Any reference to occupation in the rest of this paper assumes that its composite nature is understood.

Occupations always occur in an environment²⁰. Referred to as occupational form, the pre-existing structures and objective circumstances that exist in the external environment may elicit, facilitate or obstruct performance (Nelson, 1999). For example, a person cannot learn to use a sewing machine until they have access to one, and probably a teacher to guide their learning and skill acquisition. Variations in performance depend on the degree to which occupational form exists and whether or not the relationship between the doer and the environment supports or undermines success.

Structural, temporal and sociocultural factors all influence people's occupational performance²¹ whether they are aware of this or not. Occupational performance refers to the dynamic hub of interaction between the person, the occupation and the environment. This entails tremendous complexity, and every act has its own demands, is determined by the inherent or acquired abilities and motivations of the performer and regulated by the environment. According to Palatajko (2004:42) "much of the process of occupational performance is not readily observable or

²⁰ Environment refers to the attitudinal, systemic, legislative, structural or physical setting or context (World Health Organisation, 2001a)

²¹ Occupational performance is the voluntary doing by the person within the context of the occupational form (Nelson, 1999:77).

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knowable” because apart from visible elements “only processes that reach metacognition can be reported”. This means that further probing and analysis of the complexities of the goodness of fit between the performer’s abilities, the demands of the occupation and the accessibility (enabling participation) of the environment is indicated. Take the example of gardening in Table 1. The performance component demands change when the water has to be fetched from a distant river or, as is the case in the rural villages we visited, from a communal, more accessible water tap. The taps however do not supply water every day and are without a thread so a distribution hose cannot be fitted, which would have made a big difference to the watering of household vegetable plots. People therefore have to expend more time, energy and effort. Their performance may be compromised when they are undernourished, have an impairment or are marginalised (for example, in relation to power dynamics involved with gate-keeping access to communal resources). The point here is that much more is happening and at stake than may be immediately obvious when collecting information about what people are doing, be it associated with their personal, economic or social decisions in dealing with poverty and disability. ‘Doing’ is so commonplace that its demands and the added difficulties created by poverty and/or disability are easily overlooked. We suggest that prolonged exposure to disadvantageous conditions, resource limitations and deleterious occupational forms may lead to the stagnation of potential, stunted agency and restricted learning, creating a state of existence called occupational poverty,²² a condition in which there are fewer occupational forms (for example, too little water in the tap to maintain a vegetable garden, or no water left after one person has taken all the

²² Occupational poverty refers to a state of existence characterized by stagnated potential, stunted agency and restricted learning in the performance of roles, tasks and activities. It occurs when people experience limited opportunities; prolonged disequilibrium between doing and being and separation from their innate creativity because of structural inequity.

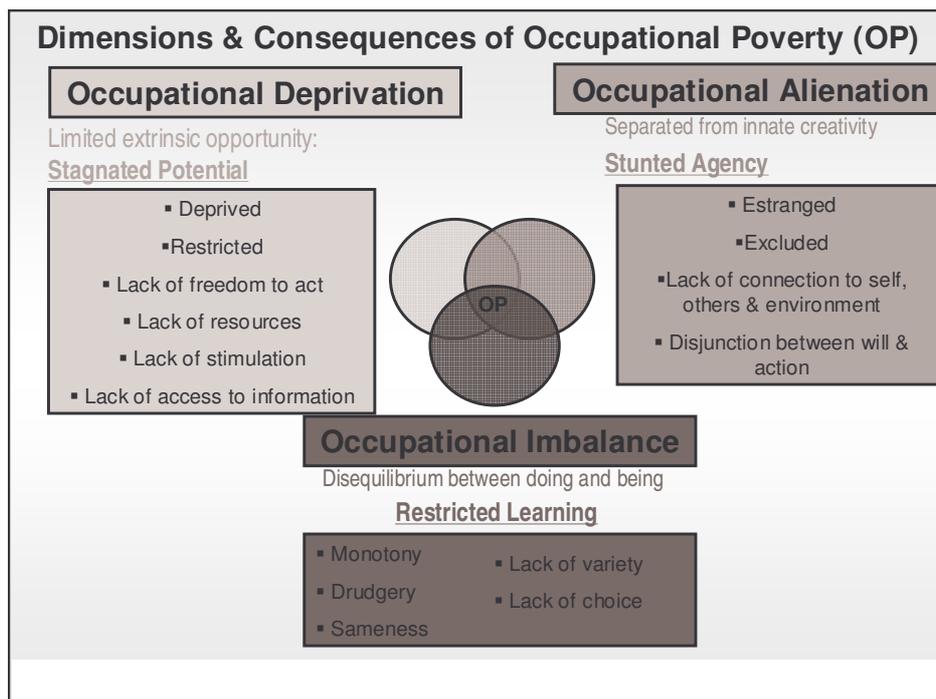
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available water), and some which might even be deleterious to occupational performance (for example polluted river water).

Occupational poverty

Occupational poverty is precipitated by limited opportunities, an enduring health problem and disabling situations and perpetuated by structural inequity and injustice. It occurs when people are deprived, over long periods of time, of fulfilling their daily roles, tasks and activities in meaningful ways.

Figure 1 : Dimensions and consequences of occupational poverty



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Three dynamically related states i.e. occupational deprivation²³, alienation²⁴ and imbalance²⁵ are used to explain how occupational poverty operates. *Occupational deprivation* occurs when the environment or occupational form deprives people, over long periods of time, of substantive infrastructure, resources and freedom needed to give expression to their developmental life tasks, interests and abilities. With limited access to opportunities for personal growth, their potential to 'become' may be in danger of stagnating. Alienation involves not belonging, not fitting in, being marginalized and disconnected from previous experiences, people and circumstances. A sense of alienation happens when people find themselves in unfamiliar surroundings or circumstances as may be the case with displaced people or following the unexpected onset of disability. *Occupational alienation* in the context of enduring poverty involves similar conditions. Being disconnected from purpose and diverted from doing valued things as a result of intrinsic restrictions eventually leaves people experiencing a sense of separation from self, others, activities or products. Characterised by stunted agency and a disjunction between will and action, occupational alienation relegates people to the fringe of society, estranged from a sense of purpose and meaning in life. *Occupational imbalance* unfolds over prolonged periods when people spend all their time and

²³ Occupational deprivation refers to being restricted, kept or hindered extrinsically from acquiring, using or enjoying innate capacities, interests and skills (adapted from Wilcock, 1998).

²⁴ Occupational alienation refers to intrinsic estrangement or diversion from innate, natural creativity leading to separation from self, others, activities or products (adapted from Wilcock, 1998)

²⁵ Occupational imbalance refers to disruption of balance or disequilibrium within or between intrinsic and extrinsic physical, mental and social abilities and needs (adapted from Wilcock, 1998).

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energy on one or just a few occupations, or have too much or too little to do. A narrow focus on repeatedly doing certain selected things may be materially effective, but limits the diversity of experience and the development of other interests. At extreme levels too much or too little occupation may have a negative impact on peoples' physiological, mental and social health and general well-being (for example, chronic diseases of life style). Occurring therefore in conditions of adverse occupational form and associated with lack of variety, people may have difficulty in forecasting, imagining something or planning for the future because of their limited exposure, opportunity and experience. Rather than boredom encouraging them to do something different, they keep to the monotony of the known. In this state, people are not receptive to learning. Being on the margins and dissociated from stimulation and positive experiences may eventually dull peoples' expectations, a view which as far as disabled people are concerned is "also often held by wider society" (Yeo and Moore, 2003:573). A closer look at individual occupational performance however often reveals agency and aspiration albeit in confined circles of influence.

Agency and aspiration

The person-occupation-environment correlation surfaces the negative ramifications of structural inequities on the adaptative abilities of disabled individuals and their households. It also exposes ways in which people calculate, adapt, modify, simplify, organize or strategise in meeting their needs and moving towards their aspirations over time. To uncover agency is to look for the big and little things that motivate people and then to discern how they act in finding practical and attitudinal solutions to everyday challenges. Agency refers to the "capacity of intention ... that is individuals,

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through rational thought, free will, motivation or emotion, are able to direct their behaviour or make particular choices" (Hayes, 2004, p. 179). Why do some people demonstrate capacity of intention by grabbing opportunities and others do not? While opportunity may make something possible, it does not necessarily bring about change because people's motivation is linked, in part, to their aspirations. Existential conditions and structural inequalities limit the scope of aspirations. For example some aspire to have two meals a day; others want a better life for their children or to make a contribution to the community. Aspirations need reinforcements such as exposure to new ideas, knowledge and the opportunity to work together with others on mutually identified goals (Nathan, 2005). Appadurai (2004) writes about the capacity to aspire as being orientated to the future, something that people who live in hopelessness have difficulty with imagining²⁶. He argues that part of being poor and weaker than other members of society means that poor people are more rigid, because they lack opportunity of "practice, repetition, exploration, conjecture and refutation" (ibid, p.69). We argue later that the facilitation of occupational performance in the context of community-based rehabilitation offers one way of supporting peoples' agency. This will become clearer in the Tole case study.

The Tole case study

The Tole household includes Ayanda and his wife Noshile, their three children (including a two month old baby) and Noshile's uncle, Molefe. They live in a remote rural area of the Eastern Cape, South Africa in a minimally

²⁶ Appadurai (2004) introduces the concept of aspiration as a feature of cultural capacity, which is not discussed here.

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furnished (one wooden bench, a chair and an old aluminium chest), mud brick dwelling with a dung floor. Wood and dung is used for fuel and cooking occurs on an open fire inside the hut. Food (such as dried maize) is stored on the roof and a zinc bath; they sleep on woven grass mats, bathe using a bucket and dress from a choice of two or three threadbare garments per person. A single, long drop toilet is available within a 100 meter walking distance. Noshile fetches water from a communal tap or a dam that is that is half-an-hours walk away. They own very few eating and cooking utensils; limited tools and have no books or bought play objects for the children. Reliant on social welfare (one disability grant and one child support grant), their reported income at the time (2007) was R1000 (GDP 80) per month, including a small sum added by Noshile from the sale of crisps and fruit in season, which she bought, repackaged and sold from their home at a small profit. They own no livestock, savings or land and are disconnected from an extended household support system due to a dispute.

From this brief description of their living environment, the occupational form may be described as deprived. The Eastern Cape is a part of South Africa that has seen great socio-political changes and remains largely underdeveloped. The District Municipality of Alfred Nzo, where the Tole household live, is a part of an area where 70% of the largely rural inhabitants have an income of <R6000 per year (Eastern Cape state of the environment report, 2004), and 47.15% of adults are unemployed (Statistics SA, 2001)²⁷. In the past many people left their villages to work in the cities, men either as contract workers or casual labourers and women as domestic helpers. With the decline in opportunities for unskilled employment the whole community has suffered. Most people are landless, and poverty is

²⁷ The census variables provided have been aggregated by Statistics South Africa (Census 2001) based on the new ward and municipal boundaries (December 2005)

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central to their lives (Lahiff, 2005). Improvements in the provision of educational and health facilities and some services have occurred, but these compare poorly with other provinces in South Africa.

When the authors first visited their home Noshile was out but Ayanda gestured that she would be back when the sun was going down. It was evident that Ayanda had not developed language due to a hearing impairment. His communication was nevertheless clear enough for us to understand. Ayanda had been deaf from an early age (cause unknown). His parents were elderly and he was their only child. He went to a special school Deaf²⁸ children, but was only there for one or two years before his parents died and he returned to his natal village, where he has lived ever since. Consequently, he never acquired language or how to communicate in the official South African sign language. He has never been formally employed, but occasionally does casual jobs such as digging trenches or mending fences. As Ayanda had promised, Noshile did come back late in the afternoon having attended a burial society meeting. Despite the households' financial constraints, part of their monthly income went to a Burial Society fund for Noshile, Ayanda and Molefe. This expense is linked to the Xhosa belief system that incorporates ancestors as spirits who communicate with God, mediating between Him and humanity into the welfare of the household (Holland, 2001). It is believed that respect for ancestors, afforded through proper burial and other observances may procure their intercession on behalf of the living.

Ayanda missed out on compulsory and inclusive education that was introduced in South Africa in 1996 (Department of Education, 2001). Unable to

²⁸ Capital "D" when referring to a person, as recommended by DEAFSA: Deaf Federation, South Africa.

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speaking his native language (he can make some sounds but not words), he relies on gesture to communicate. The system he uses is something he has developed himself and understanding is therefore largely restricted to the people who know him well enough to interpret their meaning from his accompanying gestures, grunts and facial expressions. The development of cognitive function including language is shaped by cultural influences (Vygotsky, 1978). Intellectual maturation and concept formation relies in part on language acquisition and speech development. How did Ayanda learn and continue to acquire knowledge and skills? Over the years he developed a number of livelihood proficiencies, for example how to build a mud brick dwelling, but a lack of speech and language development nevertheless placed a restriction on his whole life. The impact extends to what he can/ cannot do (for example get a job away from his village), and to his relationships. His communication outside of his household familiars is restricted to essentials, cutting him off from community participation and potential inclusion in scarce job opportunities.

Deprived by socio-economic circumstances beyond his control, excluded from connections with others outside his immediate household and faced with limited choice, Ayanda's occupational repertoire may be described as impoverished, alienated and imbalanced. Beeton (2000) suggests that the interplay between disability, occupational participation and unfavourable circumstances is at best restrictive and in extreme circumstances incapacitating. This can have a profound impact on a life, the lives of the people closest to them and ultimately on the community in which they live. What might Ayanda have achieved had he been supported by different development opportunities? Further investigation of the Tole household also reveals their agency and aspirations. Ayanda and Noshile, in aspiring to a better future, recognise latent resources in their environment; and take possession of opportunities for advancement however small these may appear

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to be. They direct their efforts, lateral thinking, problem solving and creativity towards the creation of a household through careful strategising about the use of limited resources with adaptations matched to Ayanda's disability.

When we met Ayanda he was busy building a two-roomed flat roofed structure, having done most of the work on his own. The dwelling stands on a slope and is in easy walking distance from an access road. He and Noshile formed the bricks from a mixture of mud and grass, and while these were 'baking' in the dry winter sunshine, they prepared the building site. One completed room housed the family while building continued. The other space did not have a roof although the walls were up. Noshile told us that they planned to add a room for the children later. Their three-year-old son Ludwe, spends most of his time with Ayanda because his older sister Busiwe is at school for part of the day and his mother is often out performing domestic activities.

Since 'doing' is dependent on occupational form and 'becoming' is linked to 'being' and 'doing' within the developmental process, it may be postulated that the range of what it is possible for Ayanda and his children to 'become' has limited currency. His lack of formal education, physical location and inability to communicate fully make it difficult for him to increase and broaden his abilities; it would seem that he is capable of doing and becoming more, but circumstances prevent this. A regular male wage earner who had completed primary school was found by John-Langba (2007) to significantly decrease the odds of a child being poor. While his silence might affect his children's language development (considering that this is a child's primary tool for communicating with parents and important in the zone of proximal development²⁹), of greater significance is the lack of general

²⁹ Vygotsky's (1978) formulation of how a child/learner benefits through adult guidance

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cognitive stimulation that occurs for children in resource deprived environments. An impoverished environment does not provide children with a good developmental platform, and poor schooling outcomes indicate that these deficits are not being overcome by the education system (Department of Education, 2006). "The legacy of apartheid neglect of early childhood development provisioning and practitioner training is that the most disadvantaged children have access to the poorest services." (Biersteker & Dawes, 2008:185).

Busiwe and Ludwe are learning practical things relevant to their living environment and Ludwe has an early opportunity to observe his father at work, probably in the same way that Ayanda himself had learnt. Rogoff (2003) points out that the children in many cultures enter the world of adult work and acquire skills from an early age, including the use of tools.

When Noshile arrived back home she told us that they had been forced to leave Ayanda's uncle's home where they had previously lived because they had refused to contribute all the money from Ayanda's disability grant to the general household's expenses. The couple had been saving for some time to build their own home and had planned to leave once they had saved enough. They had been contributing to the general household expenses and felt that they could not forfeit more without delaying their own plans. Forced to depart earlier than they had planned due to the dispute, they found building difficult because they could no longer call on additional labour from extended household members. The building of houses is (not state funded) and residents are required to meet all costs. The local chief allocated land to them (part of a communal area vested in the chieftaincy³⁰). Ayanda's disability grant money was stretched to the limit to provide the

³⁰ Community authority roles are not always easily discerned

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necessary building materials, as evidenced by the absence of any substantial assets in and around their homestead, but they had persevered. Once the roof was up the main room offered them shelter. They were proud of what they had achieved and looked forward to extending the dwelling as their children grew up.

Du Toit (2005) 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. The Tole's, particularly Noshile, were friendly with neighbours but could not call on the support of their relatives because the dispute had not been resolved. Social capital arises from the prevalence of trust in a society or in certain parts of it and is primarily a system of values especially social trust which is the pivotal basis of a stable social order (Field, 2003). He suggests that trust and trustworthiness are like the lubricating oil of social and economic transactions where high trust networks function more smoothly than low trust ones.

Noshile was the youngest of six children and had always lived in the same village. She was 30 years old and had passed standard 8 (10 years, two years short of completing high school. She was forced to leave because she was needed at home. Her siblings had all left the village to marry or look for work and it fell to her to care for both of her aging parents, and later to nurse her sickly mother for six years. Her mother's old age state pension had been their only means of support. At that time, Noshile's uncle Molefe was unemployed and also dependent on his sister. He had the customary right as the only older male relative to claim the homestead on his sister's death. These circumstances shaped the rest of Noshile's life when she found herself without any means of support. Her parents had managed to provide lobola (bride price) for her brothers. By the time that Noshile wanted to marry, and in the fading years of her mother's life, there were no more cattle and all

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other resources were also depleted. Shortly before her mother's death, she married Ayanda, a man 14 years her senior. She was initially not interested in him but eventually agreed to the marriage realising that once her mother died she would be destitute. Through her marriage Noshile gained access to Ayanda's disability grant.

The structure and social conditions of a society have profound psychological effects on the occupational human and on how s/he experiences him- or herself and others in relation to everyday occupations. Noshile spoke about her desire to finish school and study further so that she could make a way for herself in the future. Her situation is similar to that experienced by other women in the region following economic difficulties and the rise in the incidence and prevalence of HIV/Aids. Occurring for women at every age from birth till death, the impact of these social conditions on their health, nutrition and education has been considerable (Gwatkin et al, 2007). Women have been forced to compensate for failing family incomes, caused by unemployment and deaths, by working harder than ever. Although disability grants are not intended as a general poverty alleviation measure in reality this is how they operate. "People who apply for grants are usually poor, and the grant will often provide a livelihood for many people and not just the disabled grantee" (Swartz and Schneider, 2006:242). Noshile reported that Ayanda's disability grant was an important factor in her decision to marry him.

From talking to Noshile it soon became evident that she had many different things to attend to and that everyone in her household depended on her. In addition to her own immediate family she also supported Molefe, who lived independently in the former family homestead, by supplying him with food and tobacco. Noshile told us that he was periodically unwell and for this reason, out of respect for him as an elder and in accordance with local Xhosa

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custom of supporting their kin, they provided for him. A typical day in her life was spent making a fire, fetching water, collecting fuel, grinding maize (in season), preparing food (either maize porridge or a potage of whatever vegetables usually potatoes, cabbage or spinach could be afforded or secured), caring for the children, washing and cleaning, or attending women's gatherings. Apart from household chores Noshile also contributed to the building operation by making mud bricks, plastering the dwelling or replenishing the dung floor. Local regulations prohibited people from drawing water from the communal tap for building purposes. Their domestic tap was a short distance away from their dwelling and shared by ten other households when water was available, which was once or twice a week. On all other days water had to be fetched and carried back from a dam in a large bucket on Noshile's head, a half-an-hours walk away from their home. Some days Noshile had to make three trips. A donkey cart or vehicle could be hired, but there was rarely money for this.

Potgieter et. al. (2006:5) report that women, as opposed to men, in the rural Eastern Cape "spend all, if not most of their time and energy on routine domestic tasks...." This so-called time poverty means that they are often unable to attend to their own needs or to participate in economic activities (Ibid.). There are multiple environmental and resource restrictions in Noshile's environment. The cost and infrequency of public transport places restrictions on peoples' occupations. The water supply in the area is also an ongoing problem, both in terms of availability and potability. Plans for improvement exist (Community Water Supply and Sanitation Programme) but as implementation is slow, the scarcity of safe water has a major impact on the community's health and occupational performance. A lack of easy access to water, fluctuating supplies and the time and energy needed to procure it mostly restricts its usage to essentials. Even women who do not have very far to go to fetch water, struggle to keep their vegetable gardens

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going on the little left over after domestic needs have been met. A few people own plastic water tanks, but these are expensive and only work well if there is a proper run-off from the roofs. Peoples' powerlessness is emphasised by the fact that none of the taps have a thread for the attachment of a hose, and anybody who has a vehicle to convey their containers can come and take as much water as they need for a week, leaving the resource depleted for everybody else.

The household relied on Noshile's ability to manage their financial resources well, although the couple budgeted and set priorities together. When we first met they were saving to buy beds. Occasionally Ayanda needed help with building, for example when the roof was put into position, and he would then instruct Noshile as to whom he wanted to employ and what he was prepared to pay. She would then undertake the negotiations. It seemed that virtually everybody in the villages of the sub-district where they lived was poor and nobody would or could offer services as a neighbourly gesture. The distances from shops and other services was costly for Ayanda's tight budget, causing delays in building operations, which were problematic if the weather was inclement. The area is renowned for high summer winds and heavy rain, so it was important to have the roof secured in good time to prevent possible financial losses from storm damage. If building supplies were needed (wood for the roof supports, nails, zinc roof sheeting) she bought these from the nearest town, about 50 kilometres away. The food and general supplies the household needed were also purchased there. Shopping trips had to be carefully planned because not only did she have to pay for her own transport both ways but also for each large parcel of goods that she brought home. A trip could reportedly cost upwards of R75 (GDP27.75).

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The successful management of the household resources was evidenced by ongoing building operations for more than a year. Yet this may have come at a high price as far as Noshile was concerned. A fine balance was required to meet households needs, and the demands of building, emphasising the precarious role that this woman and others like her fulfil in a very poor rural society. So much depended on her ability to hold the household together, and while this may have given her a certain amount of satisfaction, her many duties restricted the development of her talents and aspirations.

Noshile wanted to breed chickens, while Ayanda hoped to own animals in the future. Noshile enjoyed learning to sew at school and continued to do some handwork, but wanted to learn to use a sewing machine. There were no projects in the area where she could learn and she did not have a sewing machine. She also spoke of her wish to have a vegetable garden that she could cultivate to feed her family but they did not have tools or seed. She explained that there would not be money for any of this until building was finished, and in order to start a garden she also needed to buy fencing to protect it from the local goats and sheep, which roamed around freely and might quickly destroy the plants. Until then the family would rarely have fresh food; neighbours sometimes gave her spinach and she bought the occasional onion to add flavour to their bland dishes. Despite these limitations, she and Ayanda managed to raise a maize crop once the building of the second room was completed.

Financial limitations kept Noshile from doing things that she regarded as necessary e.g. raising chickens and growing vegetables; and important e.g. sewing and making clothes. She saw these as possible income generating enterprises, was aware of the families' nutritional needs and worried about the children's limited diet. Noshile wanted to teach Busiwe the many things she would need to know as an adult.

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Unlike her brother who was lively and outgoing, Busiwe was quiet and shy. She first entered school when she seven years old. At home she was learning to help her mother with the household chores, such as washing clothes, making a fire and tending the cooking pots, all things that she did when she came home from school. When this was finished she ran off to play with other girls who lived nearby. Their favourites were hopping and clapping games, playing school by drawing in the sand, and house-house, in play houses built with discarded bricks, with a kitchen equipped with bits of paper, old tins and containers for kitchenware. Little Ludwe liked to imitate what his father was doing, but was happiest when his mother and sister were around, particularly Busiwe because she taught him how to sing. One day he was observed with a sheet of old plastic pulled over his head and shoulders, holding a stick in front of him and rhythmically chanting and stamping as he made his way around one of the huts.

At what age do children develop the ability to do household chores and how do they meet their developmental need for play and learning when the household requires their labour? It depends. Theory from middle class communities in Europe and North America has developed norms about what can be expected from people, particularly children, and that the latter are capable of certain skills at particular ages. But, human development is influenced by cultural processes and different cultural communities have different expectations about what people do at every age and stage of life. Peoples' doing relies "in important ways on the cultural meaning given to the events and the social and institutional supports provided in their communities for learning and carrying out certain roles and activities" (Rogoff, 2003:6).

Busiwe liked school but Noshile reported that she was not making good progress. There was no evidence of anything associated with schooling in

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this home or any others like it that we visited (for example homework books; crayons or paper). There was no library in the village, or indeed in the nearest town and any news or contact with the outside world was by word of mouth. There were also no children's playthings (for example balls or dolls) around besides sticks, stones, discarded objects (with which we saw children create imaginary cars and cooking games) and the local clay from which they moulded figures and familiar objects. Integrated into a routine of essential activities, Busiwe accepted her domestic chores without question. Her role as a daughter was to learn all she could from her mother and to help her obediently.

In the Vygotskian (1978) tradition the developmental context is seen as invested in local and cultural meanings. This is conveyed to children in the manner in which caregivers structure their everyday activities in the home and community (Dawes, et. al., 2000). Variations in expectations for children make sense once different circumstances and traditions are taken into account. Barrett (1997) says that children contribute to the household economy by freeing their elders to do other important things. The Tole children's activities demonstrated the influence of culturally embedded practices. For example, Ludiwe's dancing was an imitation of what male initiates do when they return to the community after a period of isolation and preparation for manhood. While these occupations afforded Busiwe and Ludwe the opportunity to acquire specific cultural and situated knowledge and skills, there was a paucity of resources and educational materials in their home and environment to stretch their learning. Early learning programmes are recognised as critical and are part of South Africa's educational plans. The Department of Education is committed to UNESCO's goal for their introduction by 2015 (Pandor, 2007). In the meantime a critical period of rapid childhood development is going unsupported and contributing to poor school results. Access to information, managing scarce resources effectively,

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investing in life-long learning and encouraging citizens to make informed decisions are some of the values that are part of a reasonably literate society (Vil-Nkomo & Myburgh, 1999). Ayanda and Noshile's limited exposure to information and intellectual stimulation beyond the immediacy of their daily lives could provide limited opportunities to equip the children for occupational participation in the wider world.

Belonging to the burial society and her church gave Noshile the opportunity to spend time with her neighbours and to do something other than domestic work. When these groups had social activities Ayanda would accompany her. They participated in village functions, including celebrations, ceremonies (to mark the stages of life and death) and those associated with rites (mechanisms for keeping in touch with the spirit world) (Holland, 2001) whenever they could. They both keenly anticipated any opportunity for singing, dancing and feasting. On such occasions the men would meet early on the appointed day to slaughter an animal. As a makoti (a young wife) Noshile was expected to help with the preparation of the food; she liked to bake bread in the open fire and assist with brewing umqomboti (traditional beer). Meat was the main attraction for everybody at communal meetings and all the villagers were welcome to come and share it, a treat rarely enjoyed by Ayanda's household at any other time.

Basic social obligations, indigenous knowledge and skills that deal with personal and collective survival are learnt within a communitarian context (Mugo, 1999). Cultural mechanisms have the potential for promoting adaptive coping and are therefore valuable for survival beyond the immediate benefits of social integration. Pityana (1999) says that the lives of African people are centred on belief systems, rituals and practices that make life meaningful and purposeful for them. These help them to cope with fear and uncertainty about the future while also creating the climate for the

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internalisation of shared norms. Cultural beliefs about disability influence how disabled people are perceived by and assimilated into society (Watermeyer et al, 2006). Noshile was responsible not only as partial caregiver but also for helping to smooth the connection between Ayanda, Molefe, and their community. She acted as their go between, accommodating the idiosyncrasies that arose from their impairments, and modelling appropriate behaviour for others to follow.

Ayanda was independent amongst his neighbours and people had learnt to understand his basic communications, but he left Noshile to deal with complicated conversations. She in turn explained things to him as best she could when they were alone. Ayanda was a willing and able worker and despite the concrete limitations of his communication abilities actively sought opportunities to add to his income. The local Chieftainess invited anybody who was willing to participate in Public Works projects to submit their names to her. She took people in rotation, trying to give everybody a chance to work. Most contracts only lasted for about three months, and each person's turn might only come round every few years. Ayanda also worked for neighbours, doing odd jobs like erecting fences and repairing buildings. Noshile complained that villagers treated him unfairly at times. He could earn as little as R5 (GDP .37) for a days work. His efforts to negotiate better terms failed because people pretended not to understand him. Noshile could not do much to change this as she did not wish to shame her husband in front of other men, but she did speak about what she saw as an unfair practice with other women.

The role attribution of 'worker' becomes stratified when competition for jobs is high; some people are more likely than others to secure 'piece jobs' based on their position in the community. Disabled men in Ayanda's community were sometimes engaged but not paid the same as other

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workers. Was Ayanda alienated from the worker role due to prejudice or misconceptions about his abilities? Was he considered unfit to do some labour at the going rate of pay because he had an impairment that set him apart from other men? We also met a number of men in their early twenties who, known to the community as 'mad' (assessed by us as mentally ill), were being paid below the going daily rate of between R25 and R50 (GDP 9.25-18.50) for a day's work e.g. collecting sand for building sites; digging trenches.

Noshile's uncle Molefe had a history of misfortunes and illness. As a young man he had held a number of contract jobs in Gauteng working as a labourer. He had been at school for four years and was then sent to herd the families' livestock, which he did until as a young man of 19 years old he wanted to see the places that so many migrant labourers in his village talked about. The jobs that he did in Johannesburg included working in two different coalmines, brewing traditional beer (for five years) and cleaning municipal toilets. This all ended in 1990 when he returned to his home village after an absence of more than two years. He was 33 years old at the time. The relationship between himself and his wife became strained and there were many fights until she left, taking his only daughter with her. Molefe recounted tearfully how much he missed her and said that she had broken his heart. He has since lost touch with her and his child.

The kind of work that Molefe had done is typical of a category of employment that engages many unskilled, semi-literate workers in the South African economy where low growth in the demand for labour is out of balance with high population growth (Erasmus, 1999). The 'cleaning of toilets' that Molefe reported was something that other men whom we met in the same area also spoke of. In terms of job security and service conditions, working for the municipality (as in cleaning public toilets)

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appeared to be amongst the better unskilled jobs available as opposed to working on the mines where retrenchments and injuries occurred. Men contracted to work on South African mines are commonly away from home for long periods and the difficulties that Molefe experienced in trying to re-establish himself domestically are not uncommon, where both or one partner has accommodated to their separation and does not welcome to reestablishment of the relationship. Reports from India, Indonesia and Tonga suggest that changes in life circumstances e.g. poor physical health, widowhood and child-loss have long-lasting implications for mental health (Das & Das, 2006). Molefe was not only crying because of loneliness. A brief history-taking revealed that he had an enduring mental illness; precipitated, according to Noshile, by the breakdown of his marriage.

When we met Molefe he was 52 years old. His deceased sister's property, where he had lived since her death, was showing serious signs of deterioration. He fetched water for himself once a week and also collected fuel to keep a fire going in his hut. When he first returned permanently to the village he had taken up his previous tasks of working in the fields and tending the livestock. Some time after that he was offered a job at a mortuary in the nearest town. This was not a success; he said that the dead bodies made him scarred of dying and he became mentally ill. The parallel history told by Noshile was that he had been behaving strangely before that. He would become confused and seemed not to hear what people said to him. At times he would rush around wildly in the open lands, laughing and singing to himself. He recounted that he had heard voices telling him to run away. When this happened neighbours would go out and look for him, try to calm him and bring him back home. At other times he would spend the whole day in bed, and refuse to talk. Neighbours wanted him to go to the

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sangoma (traditional healer) but he refused.³¹ Eventually, after a particularly long bout of crying, refusing to eat and utter loneliness, the police took him to the hospital in the nearest town, where he was given medicine, which helped him function again. He began to be seen walking around again, although he seldom did anything other than wander or sit and share a cigarette with other men; reportedly not saying much. Over time these episodes of illness and recovery became features of his life. He would be calm for a while and get along with relatives and neighbours and then suddenly his behaviour would change, and the whole cycle would be repeated. When Noshile saw that he was not well she would take him to the clinic sister, who gave him an injection. He had no income and relied on Noshile as well as neighbours to do what they could for him, giving him clothes and sharing food. Throughout all the years of his illness it was reportedly never suggested that he might apply for a disability grant. He was aware that his dwelling needed repair, but said that he would get 'the women' to do the necessary work if he had money to pay them. He spoke about growing vegetables, but the property needed fencing, and he had no money to do this or to buy seed. He mentioned that he would like to marry again but did not have the means to pay labola (dowry). His summary of life was "all days are the same. My heart is down because of my situation".

Mental health services in the Eastern Cape are inadequate. Sub-district clinics are established in the area but not serviced by doctors. Nursing sisters, most of whom have limited mental health training or experience, are responsible for detecting mental illness and dispensing psychopharmacological medication. The police service does offer help; their role it is to transport a

³¹ The behaviour described is typical of a mood disorder, probably bi-polar. Appropriate drug intervention can be effective in regulating mood changes and promoting function but the condition may be chronic.

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person who is mentally ill to hospital for observation if their life or that of others is endangered (Mental Care Act Section 40, 2002). A person so admitted will stay in hospital for 72 hours for assessment and treatment. If this is a district hospital, there are no psychiatrists available and specialist care (for example psychotherapy, family therapy and psychosocial rehabilitation) is rare, even in the regional psychiatric hospital, where admissions can be three months or longer. People who have been diagnosed are often sent home heavily sedated and none the wiser about their options for attaining and maintaining their mental health. None of the people affected by mental illness that the researchers met knew anything about the medical causes of mental illness, its course, prognosis or treatment. Some explanations they provided were associated with beliefs about bewitchment and special powers afforded to individuals by their ancestors. When bio-medical information was offered it had to be tempered with appreciation and respect for traditional beliefs and for the explanations that may have been given by customary healers. Based on observations, the incidence of substance use (marijuana and traditional alcohol) appeared to be very high, especially amongst young males.

Molefe's condition was not recognised or medically treated for many years. Household survey-based studies, which focus on adverse economic 'shocks' seldom identify mental illness, nor do they distinguish between common, transitory and severe disorders. There is also persistent confusion between intellectual impairment, epilepsy and mental disorders. These conditions are often misdiagnosed, inadequately treated and left to householders to manage as best they can, leading to serious repercussions for the person concerned, including their emotional, social and economic capabilities (WHO, 2001b). The neglect of mental health issues within poverty surveys may reflect the lack of political will to incorporate the voice and needs of

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this particular marginalised group. It also resonates with the politics of displacing the burden of social responsibilities away from the state, urban areas, corporate employers etc. onto rural women. Marais (2007), referring to the treatment of HIV and Aids in South Africa describes this as “buckling”, where the State redistributes risk and responsibility into people’s homes, contributing to the collapse of households and reinforcing inequality.

Das and Das (2006) argue that poverty may lead to mental health disorders through stress or deprivation, or lower the likelihood of individuals receiving effective treatment. In fact, more people receive mental health services in developed countries than in developing countries (WHO, 2004). Anti-psychotic medication regulates symptoms and therefore enables performance, but the importance of treatment in promoting people’s independence and possibly even productivity is still not always appreciated. An occupational perspective enables the view that mentally ill people are ‘doing beings’ and recognizes the occupations that are embedded in everyday roles, tasks and activities. These can be harnessed to achieve some income, albeit in sporadic, modified and idiosyncratic ways. Modern medication and appropriate treatment have enabled many people with a history of mental illness to lead independent lives and to work (Van Niekerk, 2004).

Questions arise here about the cost of “withholding” appropriate treatment and the lack of access to a disability grant, circumstances that could have made a considerable difference for Ayanda and his immediate family with respect to Molefe’s needs. Molefe, Ayanda and their community would have benefitted substantially from a Community-based Rehabilitation Programme (CBR) geared to facilitate their incorporation together with their neighbours into productive living (addressed later).

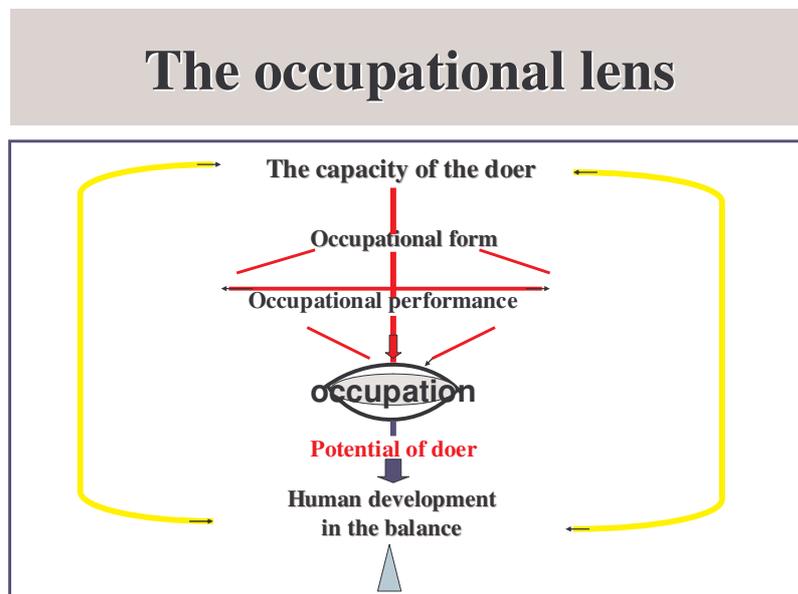
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“When we show that people with neuropsychiatric disorders can be productive, then we will have greater interest “(Baingagan, cited in Miller, 2006:461).

An occupational lens

We summarise the Tole case study using Figure 2 as an occupational lens³².

Figure 2 : The occupational lens



The lens focuses on factors that can both support or restrict the household's progress in managing the combined impacts of disability and chronic poverty. While restrictive factors dominate their story, they nevertheless maintain a precarious survival, making miniscule progress towards a limited

³² See ¹⁰ for a definition

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range of aspirations such as getting their dwelling extended; saving for beds and starting a maize crop.

Table 2 : An occupational lens on the Tole household

OCCUPATIONAL LENS	TOLE HOUSEHOLD	
	Restricting progress	Supporting progress
Capacity of doer(s)	<p>Ayanda has limited education; no skills besides those such as building mud huts, fencing with thorn branches and digging trenches that he has acquired through trial and error; he cannot communicate fully with his children and or converse with strangers</p> <p>Molefe's is subject to periodic bouts of psychosis and dependency. The householders (and community) lack knowledge about Molefe's enduring illness & limited health seeking behaviours</p>	<p>Supportive household (primary) relationships</p> <p>Noshile has 10 years of education; she uses her literacy to manage household finances</p> <p>Children are happy & reaching some of their developmental milestones</p> <p>Busiwe attends school; a new baby is healthy</p> <p>Agency: financial strategising to secure building materials; hard work & determination to achieve aspiration (what Ayanda and Noshile hoped for- their own home)</p>
Occupational form: (structural, temporal, sociocultural)	<p>Insufficient and poor quality food;</p> <p>Difficult access to clean water;</p> <p>Costly transport to nearest town</p> <p>No employment opportunities</p> <p>Restrictive socio-political & historical locality & authoritarian local governance: reportedly no access to key community structures or leaders</p> <p>Genderisation of social norms curtail access to assets: Noshile left her natal home when her mother died as it was passed on to Molefe as elder uncle/male)</p> <p>Isolated: no support from extended household members/relatives</p> <p>Subjection to community prejudice about mental illness and deafness</p> <p>Lack of knowledge about rights and difficulty in accessing these: Molefe has no DG; neither he nor Ayanda has membership or knowledge about Disabled Peoples Organisations (DPO's); & support structures incl. CBR</p> <p>Isolation from information beyond micro context of home/village</p> <p>Little intellectual stimulation beyond immediacy of home/village: no books/radio/local newspapers</p> <p>A drab & featureless physical</p>	<p>Ayanda and Molefe have sporadic access to and fair remuneration for piecework when available (allocated by tribal Chief who acts on behalf of municipality/district public sector sub structures)-</p> <p>Part of a small interdependent cultural community albeit on fringe</p> <p>Noshile is member of a burial society & church group</p> <p>Ayanda & Molefe are known to clinic sister & community health worker</p> <p>Ample physical space: planted maize for the first time and got a good yield; could establish vegetable garden if they could afford fencing and had access to water, tools, seed, pesticide etc.</p> <p>Regular social security grant (one disability and one child support grant)</p> <p>Own living space: can regulate own time and</p>

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	<p>environment in the homestead: very hot in summer, very cold in winter Health risks: make fire inside dwelling using dung or wood fuel; children play around open fire; inhale smoke (accident /respiratory risks) No savings; ancestral land or livestock Noshile wants to learn to sew and grow a vegetable garden but has no materials and tools & nobody to teach her</p>	resource use
<p>Occupational performance (incl. performance components / abilities)</p>	<p>Ayanda's never learnt sign language; this and a hearing impairment prevent him from being included in social contexts and performing income generating tasks that rely on special training & communication Molefe's thought disorder, labile mood, avolition, 'strange behaviour' etc. impair his productivity, personal & social functioning. Molefe experiences occupational poverty</p> <p>Doing: the pressing burden of physical survival dictates the monotony of repeated tasks and activities Being: life yields scant intellectual stimulation and little time for the pursuit of active learning & personal development through creative pursuits Becoming: static & precarious. High degree of vulnerability places ceiling on type & realisation of aspirations and on children's intellectual development Deprivation: occupational form curtails options (see above) Alienation: disability experience marginalises household Imbalance: note role over/underload between genders (section below).</p>	<p>Ayanda's physical labour and skills is pivotal to the construction & maintenance of the dwelling/maize crop Ayanda takes good care of the children when Noshile is out collecting fuel, water, attending meetings etc. Noshile's productivity ensures subsistence of household Noshile's social functioning builds bridges on behalf of Molefe and Ayanda into the community Busiwe & Ludwe play creatively with available materials Molefe is independent in self care and maintains his own dwelling. He occasionally helps with tasks</p>
<p>Occupation (roles: associated tasks & activities implied)</p>	<p>Disability identity: 'Deaf' and 'mad': relegated to marginal roles in social contexts: restricted inclusion & participation</p>	<p>Noshile: mother, wife, niece, income generator, cook, friend, dwelling builder / plasterer, cleaner, homemaker, homestead maintainer, clothes washer, water bearer; fuel gatherer; disability broker, carer, maize grower, burial society & community member, church member Ayanda: father, husband, provider (DG), dwelling builder, maize grower, occasional community</p>

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		<p>member Molefe: uncle, occasional community member Busiwe: daughter, childminder, learner, playmate, novice homemaker Ludwe: son, brother, playmate Baby: the new arrival</p> <p>Income generation: Noshile uses portion of grants to seed a small business of selling repackaged sweets and crisps</p>
Potential of doer(s)	Unknown due to impact of particular occupational form	Emergent and dependent on external change
Development trajectory	Compromised	Surfacing and awaiting more support

Table 2 captures some of the dynamic relationship between poverty, disability and occupation in a particular context. "Poverty is not simply the consequence of a lack of resources. Some people are unable to access existing resources because of who they are, what they believe or where they live. Such discrimination is a form of exclusion and a cause of poverty" (DFID, 2000:14). The Tole's history demonstrates their considerable capacity to deal with difficult circumstances, but their achievements should not detract from the insecurity of their situation and their vulnerability. They have a steady but inadequate income and a home but very few material assets. Their social capital and sense of belonging is tenuous. They are not connected to an extended household whom they can approach for material or other support and neighbours are not perceived as helpful. Neither Ayanda nor Molefe have any particular standing in the community; both are tolerated but disregarded when it comes to inclusion and equal opportunities (jobs are scarce for everyone and they are relegated to the back of the queue). The oldest child will probably be dependent for at least another ten years, by which time Ayanda will be 55. Their occupations are effective, but costly in

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material and human resources, and satisfactory for the present but not necessarily sustainable. Despite this, they do have a regular income through the Disability Grant (DG) and the Care Dependency Grant (CDG), but disability also has associated costs. This is discussed in the section below on Disability and Poverty.

Viewing the six people in the Tole household (including the new baby born a year after our first meeting) through an occupational lens reveals a narrow, tenuous and poorly supported life space dominated by an ongoing struggle for subsistence, offering each person a restricted range of prospects to learn and grow as an individual. There are two disabled people in this number, but in reality they are all affected by the same disadvantages. Their lives are contained within a small familiar and isolated routine, which presents them with limited participation options in the broader community. As they enact the impact of Ayanda's deafness their ability to adapt and change in response to circumstances remains precarious given the dependency of poor people on social reciprocity (Wilkinson-Maposa et.al., 2005). Their growth and development of latent potential is diminished by their personal, social and structural limitations, all of which they are likely to carry with them into a bleak future. This should be seen against the background of Molefe's enduring illness and ageing, the absence of any employment prospects or income generation beyond the confines of Ayanda and Noshile's experience and immediate environment, and their continuing and even increasing financial hardship, for example if and as the family grows. To this must be added the structural, social, political and organisational context, which caps their lives with an insurmountable barrier of powerlessness.

Davis (2006:31), who examined the life trajectories of people in Bangladesh, found that "harmful (both idiosyncratic and covariant) crises tend to be

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socially structured and disproportionately experienced by the power-resource weak.” When people (the power-resource weak) who had no insurance (such as relationships with powerful people) or other form of support were exposed to crisis, their wellbeing was affected, making them more vulnerable to further crises. May and Woolard (2007) reported (from panel data collected over 11 years in Kwa-Zulu Natal) a correlation between low initial education and persistent poverty. Education is a source of power. Noshile has been able to use her education to scaffold her household: she calculates and manages their finances and has the power to negotiate with subcontractors on behalf of Ayanda. Any negative change, such as a health crisis, a natural disaster or conflict within or outside of the home could rapidly undo the household. Furthermore, the parent’s occupations are being passed on to their children, ready-made models for the same lifestyle. The pro’s and cons of the adult Tole’s occupations speak to the possibility that their children will inherit their parent’s poverty.

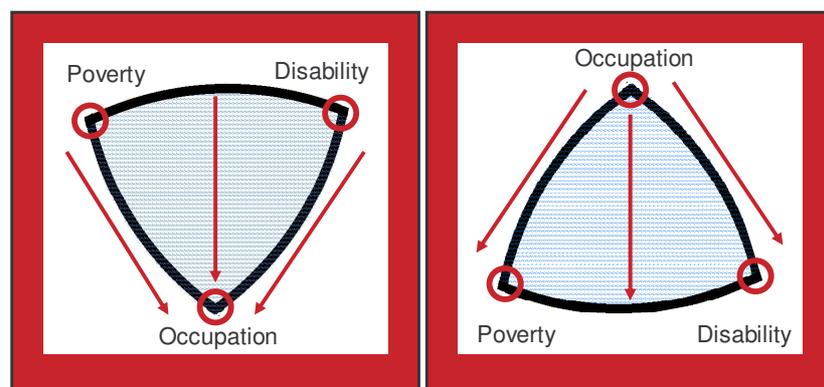
Poverty, disability and occupation (PDO)

The Tole case study has illustrated how poverty, disability and occupation are related. Figure 3 captures ways that poverty and disability play out into occupation and vice versa. Any one of the three domains might be at the base or the pinnacle of the figure depicting the PDO interaction. Whereas the direction of the arrows in the left-hand section emphasise the influence that poverty and disability can have on occupation, the right-hand side suggests that occupation might shape poverty and disability either positively

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or negatively. The PDO research in the Eastern Cape (from which the Tole case study was drawn) revealed the limitations imposed by occupational poverty, as reported in both what people were and were not doing (Watson, 2008).

Figure 3 : Interaction between poverty, disability and occupation



Disability and poverty

Defining disability is complex and controversial. There is increasing recognition that the term 'disability' does not simply express a medical condition but is rather the outcome of complex interactions between the functional limitations³³ which arise from impairments in a person's body functions or structures and the social and physical environment in which s/he lives and participates (WHO 2001a). Known as the social model of disability (Barton & Oliver, 1997), this politically orientated understanding of disability

³³ An inability to execute age and developmental stage appropriate roles, tasks and activities

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calls on society to change its attitudes and structures to accommodate disabled people rather than for disabled people to put up with exclusion on the basis of their difference. It would be wrong to assume that disabled people's occupations cannot be viewed through the same occupational lens as anybody else's'. This is not to deny that impairment will usually result in some activity limitations that would be aggravated by an unaccommodating environment. Most disabled people possesses the capacity for occupational engagement (even if they are care dependent). Their marginalisation therefore results in an immeasurable loss of potential and productivity, both of which are linked to peoples' health, well being and occupational development.

The social model of disability identifies three major types of discrimination: institutional, environmental and attitudinal (Ashton, 1999). Institutional discrimination exists, for example, where there is no legislation for equal opportunities, as might occur with respect to employment opportunities. Environmental discrimination excludes disabled people from access, e.g. a wheelchair user may not be able to get up stairs, visit neighbours or the local clinic due to the inaccessibility of the terrain. Attitudinal discrimination is relational and expressed through fear, condescension, or embarrassment when somebody meets a disabled person, resulting in intentional or unintentional exclusion. The three forms of discrimination speak to the need to address the equality of citizens in a democratic society. They also highlight the restrictions which can impact on people's occupations.

Cultural differences in interpretation of an illness or impairment³⁴ may make the lives of disabled people more difficult because they influence people's help seeking behaviours. This could be with respect to a specific

³⁴. A physical and/or psychiatric problem which affects how the body or mind works, and therefore also behaviour

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health condition³⁵, or attributable to the way particular beliefs, values and customs intersect. For example, when asked what had happened to his eye, which was clouded and sightless, a man replied that a tokoloshi³⁶ threw dust into it when he was a little boy. Different world views about causation lead to different health seeking behaviours, as with a young man we met who had a history of epileptic seizures. His mother sent him for training as a traditional healer, believing that he had special powers. The seizures remained untreated while he underwent training, the probable long-term impact being a reduction in his functioning and well being related to pervasive neuronal damage. Information, health education and disability awareness-raising play an important role in interrupting the poverty-disability link.

Roseveare and Longshaw (2006:14) indicate the need for research to establish “why so many disabled people live in chronic poverty; how this can be remedied; and why national disability policy so often fails to deliver real benefits to them.” They comment (citing Dube) that “even in South Africa where national disability policy and legislation is advanced, there is evaporation at implementation level.” South Africa is a signatory to the Convention on the Rights of Persons with Disabilities (UN, 2006). The convention consolidates all matters pertaining to disabled people and undertakes to “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity” (Article 1). The following statement appears in the preamble along with 24 others: “(t) *Highlighting* the fact that the majority of persons with disabilities live in conditions of poverty, and in this regard recognizing the critical need to address the

³⁵ The state of a person’s health and whether or not disease, illness, disorder, injury or trauma is present

³⁶ Tokoloshi is a small man with mystical powers who can appear and disappear at will

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negative impact of poverty on persons with disabilities". What's the point? Despite intended change concrete evidence of implementation of this and other international statements of solidarity and intention are dismally slow in South Africa. The Continental Plan of Action for the African Decade of Persons with Disabilities (1999-2009) (African Union, 2006) is however a structured attempt to support and encourage change, most of which is being led by disabled peoples' organisations (for example electronic distribution of information between countries, including publications).

Reliable data on the incidence and prevalence of disability is not universally available. "Disabled people are so seriously excluded from all areas of society that there is not even comparable or reliable data on incidence, distribution and trends of disability, let alone the extent of disabled people's poverty" (Yeo, 2001). There are many reasons for this but the most limiting is that there is no general agreement on the definition of disability (definitions change according to the purpose for which they are used). This means that survey concepts, design, and methods vary considerably between countries (Yeo and Moore, 2003). A difference in the definition of disability between the 1996 and 2001 South African census meant that results could not be compared (Statistics SA, 2005).³⁷ The Community Agency for Social Enquiry (CASE, 1999) undertook a South African survey using a functional screening tool in which the focus fell on people's activity participation and limitations rather than a medical condition. They estimated that 5.9% of the population had a moderate to severe disability. The 2001 South African census used the following question: "Does the person have any serious disability that prevents his/her full participation in life activities?" The classification included sight, hearing, and communication, physical, intellectual and emotional disability and yielded 5% prevalence from 2 225 982 respondents

³⁷ The 2001 definition of disability was more inline with present understanding of the meaning of disability, whereas the 1996 definition was based on categories of impairment.

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in a total population of approximately 44 million. Note that the Census defined 'disability' as a health condition or impairment and not as a social problem.

Disabled people, security and employment

Adults (age of 18-59 years), who are unable to support or maintain themselves financially by being employed, self-employed, living off the land, providing services to others or receiving external financial support (e.g. Motor Vehicle Fund), due to disability, can apply for a social security grant (Departments of Social Development and Health, 2005). If awarded it will be temporary or permanent, the former accommodating a time limited need or the anticipated recovery of functional abilities. The number of Disability Grant (DG) beneficiaries has increased steadily since 1997, and in 2004 the total was 1 270 964. Of this number 38.1% were issued in the Eastern Cape to 301 415 people (Treasury Report)³⁸. Officials acknowledge that the totals include some people who are not disabled and a periodic review process is attempting to deal with this problem. Plans are also currently under consideration by the Department of Social Development (2008) to introduce a Chronic Diseases grant³⁹, offering some support for this group of people with such conditions without drawing funds away from the disabled community.

The Disability Grant (DG) is a positive contribution to disabled peoples' welfare, but in conditions of chronic poverty the money is usually used as

³⁸ The Eastern Cape population comprises 17% of the total population.

³⁹ Plans are currently under consideration by the Department of Social Development (2008) to introduce a Chronic Diseases grant.³⁹ This would take some people with such conditions e.g. diabetes, hypertension and epilepsy, out of the DG pool. It would also provide two means of support in the future

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poverty alleviation for the whole household, and the disabled person does not benefit as intended. Yet, the whole of a household experiences the problems and privations of having a disabled person amongst their number at multiple levels, for example space to accommodate a wheelchair; hygiene and physical care for somebody who is not independent in these functions; the constant watchfulness required if somebody is exhibiting strange behaviour so that they do not harm themselves or others. Difficulties arise when the disabled person's particular needs do not take priority over other needs e.g. money for taxi fares to attend the clinic or hospital; visits to the samgoma; special equipment not covered by the health system. However, the regular income seeds activity and generates circulation of money within the household, having a ripple effect on livelihood transactions from which everybody may benefit.

The employment status of disabled people warrants special consideration because it is a matter often misunderstood. There is increasing awareness that not all disabled people need to remain on DG's for life and that employment is possible for some provided suitable and reasonable accommodation of their needs is available. "The comparison between disabled and non-disabled persons with regard to age, education attainment and employment indicates that disabled people were generally older, a significant percentage had no schooling (30%), and about 18% were employed, compared to 35% for the rest of the population" (Statistics SA, 2005:35). Some plan similar to the Expanded Public Works Programme (EPWP) launched in 2003 as a short to medium-term response to high unemployment and marginalisation, to provide training, work opportunities and an entry into the labour market for poor, unemployed people (Altman, 2007), is needed for disabled individuals as well. Given the cost, size and targets of the EPWP this is unlikely to happen and alternative plans will be

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needed that address the specific needs of disabled people before their integration into mainstream society can occur.

Disability and occupation

Occupation and disability influence one another positively and negatively. Disability creates functional limitations but some limitations can be modified or overcome through rehabilitation by adapting the way in which people do things. Most disabled people “will have a relatively stable level of functioning and changing levels of disability based more on environmental factors, such as transport, level of employment, accessibility of buildings, attitudes of society, and so on” (Schneider & Goudge, 2007:14). External factors can facilitate or restrict occupations by, e.g. the availability of assistive means and devices such as a modified environment, adapted clothing, a guide dog, a hearing aid or a picture memory board. Individuals with emotional and psychiatric difficulties are usually physically able to do things for themselves but the anxieties and fixations caused by their illness e.g. disturbed thought processes; hallucinations or delusions, can distract them from even the most basic daily activities (eating, personal hygiene), such that they need assistance or support.

The structural context is the strongest limitation that confronts disabled people, creating barriers to their inclusion by disregarding their particular needs. People with independent means are not free from these adverse influences e.g. restricted access to public transport and intolerance for ‘strange’ behaviour; but may have more alternatives available to them. Chronically poor disabled people do not have a range of options to draw on when confronted with limited opportunities, resources and choices. The following case example is taken from an interview with a 45 year old man

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who suffers from arthritis. He found himself in dire need of support as somebody living completely alone with no job, no income and no assets other than a place to live (minimally furnished), a plot of land and a few hand tools? He had stopped working thirteen months before being interviewed by the researchers when the joint pains became too severe for him to continue working as a manual labourer. His disability grant application was rejected, and he survived through the goodwill of neighbours, from whom he received bean seeds, which raised a crop, and food. He could not offer any service to recompense this kindness because even tilling his own plot was physically very difficult for him. He admitted to stealing food if none was forthcoming from other people. Daily tasks like collecting fuel and fetching water were very taxing; he was unable to perform the occupations required to meet his needs. He was living on the fringe of his community, unable to provide for himself, denied the social support which he appeared to deserve (a DG), and constantly worried about what was going to happen to him. Yet previously for at least 25 years he had been an independent and productive person. Now he was occupationally alienated from all that had been familiar to him, and deprived from exercising occupations that would satisfy his needs. This estrangement forced him to exist in a state of occupational imbalance. The result of these combined adverse influences was deterioration in his physical and mental health, created by a number of disabling factors from which there was no apparent escape.

Interrupting the PDO interaction

Yeo and Moore (2003) describe two cycles of interaction between poverty and disability and vice versa. The first describes a cycle of impairment, leading to disability and discrimination, which feeds into people's reduced

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capacity, and in turn reduces their income generating opportunities, leading to income poverty. This process may become intractable leading to chronic poverty and setting in motion a cycle of further exclusion that is difficult to break. In the second cycle chronic poverty is depicted leading to exclusion which in turn fuels conditions for higher risk of impairments that lead to disability and discrimination, further exclusion and income poverty. Perpetuating the cycle are structural conditions such as malnutrition, lack of basic sanitation, limited access to preventive health 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. These cycles are clearly complex, multi-faceted and structural and likely to differ depending on context.

We suggest that an occupational approach is particularly pertinent for a more nuanced understanding of how the disability/poverty and poverty/disability cycles proposed by Yeo and Moore (2003) affect individuals and their households. The link between impairments, activity limitations⁴⁰ and occupational disruption can be held back, limited and even prevented if the problems which occur are appropriately recognised and remediated. Health incidents such as mental illness or head injury may for example affect a person's ability to manage time, either because his or her sense of time becomes distorted (for example as a result of reality disorientation or thought disorder) or because the time needed to perform tasks changes (for example as a result of avolition, psychomotor retardation or muscle spasticity). These impairments may lead to activity limitations such as the inability to do household chores; use public transport or perform work related tasks. By preventing prolonged disruption of daily occupational routines, maintaining productivity and facilitating participation,

⁴⁰ Activity limitation refers to difficulties in managing ordinary every day activities independently, even with assistance

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deterioration into a chronic health condition, disability and eventual dependency on the State for a DG may be avoided or curtailed. To illustrate this, we quote from another one of the PDO study participant's stories. As a successful sangoma she had been travelling regularly to Cape Town, Durban and East London to offer her services. This all changed when she fell into a fire (during an epileptic seizure) and severely burnt her right dominant hand. She received treatment to heal the wounds but not to restore her function (she should have received hospital and community-based rehabilitation⁴¹). Her hand eventually became claw-like and non-functional. As a result of this she gave up her practice and became dependent on a DG in her early 40's. She has two dependent children.

When a household's income is reliant on the affected person's labour it becomes critical for him or her to access appropriate health and social services such as medication/traditional care; counselling, and hospital and community based rehabilitation as soon as possible. People's ability to get the help they need and are entitled to depends on information and all the other factors mentioned earlier, which are compromised by the poverty experience. Irrespective of what predisposed or precipitated the illness incident, it is likely to be perpetuated or exacerbated by the absence of appropriate and effective structural systems eventually feeding into the cycles referred to above.

Three factors impact markedly on the maintenance of health and the prevention of disability in the presence of poverty (Erb & Harris-White, 1999). These are direct treatment costs including travel and access, which usually force disabled and destitute people to depend on others for help; the indirect costs accrued by carers; and lost opportunities for future income,

⁴¹ Community-based rehabilitation = rehabilitation that occurs in the person's living environment as opposed to CBR, which is a development strategy definition in footnote 12

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both of the sick/disabled person and the carer. Effective health promotion, prevention and treatment, including rehabilitation⁴², is vital to enabling disabled peoples' fullest possible recovery and future participation in everyday occupations. Health promotion is about educating people so that they can take responsibility for their own health through the things they do including changing their behaviours; e.g. effective ways of dealing with conflict; the association between smoking and chest diseases. Prevention is associated with maintaining functioning e.g. general fitness; avoidance of loss of abilities, such as movement post injury, and social interaction, but poverty is a barrier to these and to treatment (BasicNeeds, 2008). Only 2% of disabled people in developing countries who are in need of rehabilitation receive any meaningful service (Krefting and Krefting, 2002; WHO 2003). "The vast majority of people living with disabilities can still not access even basic rehabilitation services, nor participate in school, training, work, recreation or other social activities" (Kronenberg et al, 2005, p5) (see Figure 3). An estimated 1.5% of any population require rehabilitation services. "In a worldwide review conducted on access to rehabilitation services in the health sector, South Africa is reported to provide services to between 21% and 40% of disabled people, higher than most developing countries" (World Health Organisation, 2002 cited in Misbach, 2004:1), but not adequate for the need, especially in remote rural areas of the country.

⁴² "Rehabilitation is a process aimed at enabling persons with disabilities to reach and maintain their optimal physical sensory, intellectual and psychiatric and/or social functional levels, thus providing them with the tools to change their lives towards a higher level of independence. Rehabilitation may include measures to provide and/or restore functions, or compensate for the loss of absence of a function or a functional limitation. The rehabilitation process does not involve initial medical care. It includes a wide range of measures and activities from more basic and general rehabilitation to goal-orientated activities, for instance vocational rehabilitation". (United Nations Department for Policy Co-ordination and Sustainable Development, 1994: 1).

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There are many difficulties related to rehabilitation service provision in the Eastern Cape Province, but just a few will be mentioned. Each of the following problems is related to structural anomalies that illustrate the current siloed and fragmented character of rehabilitation services.

- i) Access: State health services are organised according to the Primary Health Care system. This operates at different levels from basic clinic services to highly sophisticated hospitals. Patients are expected to be able to access services between these levels (albeit through a system of referrals). This can be daunting and sometimes impossible for an individual, who must try to understand what treatment is being offered and why, find the money to travel, locate services in large and unfamiliar places, etc.
- ii) Policy: Each Province organises rehabilitation services slightly differently but in line with the National Rehabilitation Policy (2000). In the Eastern Cape rehabilitation is part of the programme that includes chronic diseases of lifestyle and geriatrics. This places rehabilitation in an unequal relationship with these other services; while they share a health promotion focus, the tasks of rehabilitation are unique.
- iii) Funding: A budget is allocated for the provisioning of assistive devices⁴³ throughout the Province, but all other rehabilitation services are funded at a District level.⁴⁴ All other costs e.g. equipment, additional staff and the transport that enables community visits, are budgeted for by District-based therapists. Where there is no therapist or no staffing continuity there is no funding to support development.

⁴³ An assistive device is any equipment or apparatus that helps a disabled person to function e.g. a walking stick, wheelchair, hearing aid.

⁴⁴ Personal communication, Ms J Gysman, Deputy Director of Rehabilitation services in the Eastern Cape

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- iv) Staffing: Rehabilitation is bolstered every year by the compulsory community service placements. This brings therapists (and other health professionals) into the Province, but the majority do not stay beyond a year.⁴⁵
- v) Power: Most peoples' perception of 'treatment' is of something done to them e.g. medicine that will make them better or a procedure that will solve the problem. Rehabilitation on the other hand requires the patient to participate and eventually take responsibility for his/her own recovery.

The purpose of rehabilitation, whether hospital or community based, is to help disabled people to regain function and resume their former way of life, or develop compensatory strategies that enable them to do things differently. This is compromised under existing circumstances. We suggest that closer collaboration between all stakeholders in line with the CBR community development approach, which embodies a shifting emphasis from a medical to a socio-political model of disability (Fransen, 2005), would go a long way to changing the impasse at a systemic, structural level.

The establishment of the Office on the Status of Disabled Persons in the Presidency gives recognition to disabled citizens and provides access to all government departments. Their brief is the monitoring and co-ordination of the fundamental rights of disabled people, but the matter of equity versus equality is always difficult to balance. Good coordination between

⁴⁵ One year's community service is required of all graduate health professionals before full registration with the Health Professions Council of South Africa

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public service sectors is essential to address the impact and redress of poverty and disability, for example between the departments of Education (literacy); Health (treatment and rehabilitation); Social Development (poverty alleviation programmes); and Labour (skills training). This is not occurring as it should in South Africa but awareness of its importance and attempts to address these issues are emerging (Department of Social Development, 2006). Commenting on the link between grant beneficiaries, poverty alleviation and economic activity, the Department of Social Development (2006:2) concludes that "Unlike most of Government's poverty alleviation measures, the social assistance programme was not specifically designed with exit strategies for beneficiaries, other than a change in their living circumstances and income levels. There is a lack of a proactive and deliberate strategy to link social grant beneficiaries to opportunities for economic activity. Consequently, an intolerable proportion of able-bodied poor South Africans (inclusive of caregivers of children receiving the child support grant) and those persons with disabilities capable of rehabilitation continue to face particular barriers to entering into, remaining in and progressing in such employment." Community-based rehabilitation helps to bridge some of these obstacles as well as providing a service directly applied to the person's living circumstances.⁴⁶ This then is where the person's occupations of everyday life and their functional recovery meet, because occupational performance requires a dynamic interaction between people and their environment. Many obstacles will need to be overcome before implementation, but some small beginnings where resources and structural support is available may yet be possible.

⁴⁶ See Figure 5 below and the left hand column re Health services.

Facilitating occupational performance

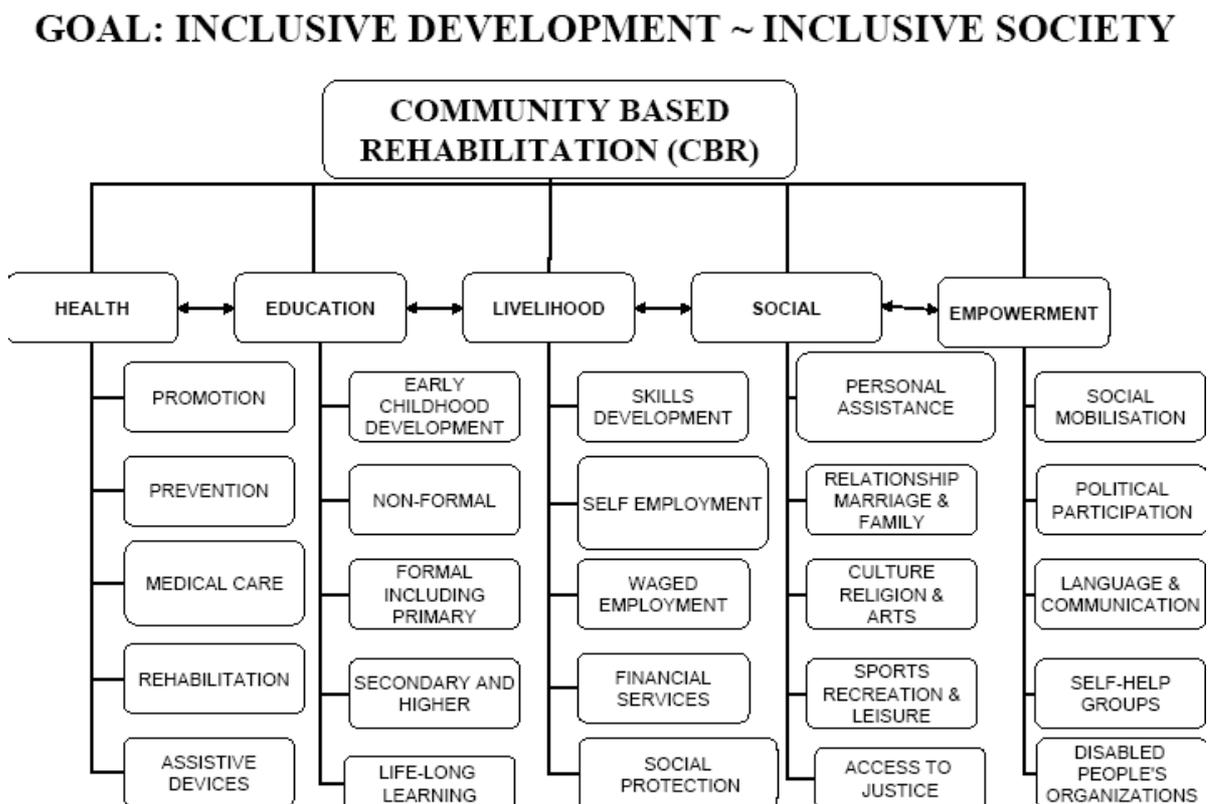
Throughout the paper we have emphasised the necessity for change to occur in the situation as we experienced it in the Eastern Cape village amongst disabled people and their households. We suggest that this needs to occur in a particular way. Change should be process focussed because it is the only way that positive adjustments, modifications and alterations will become sustainable. Transformation implies ongoing independent development, seen within an occupational context as progress towards people doing the things that will make a significant difference to the sort of future that they envisage for themselves, those close to them and their community. It is essentially an individual journey, which can and will have group and community ramifications. Community Based Rehabilitation (CBR) is often claimed to be the best approach to inclusion and social integration. The WHO believes that it promotes and protects human rights while creating equal opportunities and making the best use of scarce resources (DIFID 2000). Community-based Rehabilitation (CBR)⁴⁷ was originally intended as a service primarily for disabled people and their families, but has now been re-envisioned to embrace a multi-sectoral approach. This includes communities, government departments, Disabled Peoples' Organisations, Non Governmental Organisations, and the private sector as well as disabled people and their households. The core ingredients of a CBR programme are cultural compatibility and the use of local resources. Programmes share principles of participation, inclusion, sustainability and self-advocacy (ILO/UNESCO/WHO, 2004) and have much in common with health

⁴⁷ See footnote 18 p6 for a definition

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promotion, emphasising empowerment, enablement and social justice (Thibeault & Hebert, 1997).

Figure 4 : The Community Based Rehabilitation Matrix: ILO/UNESCO/WHO (2004)

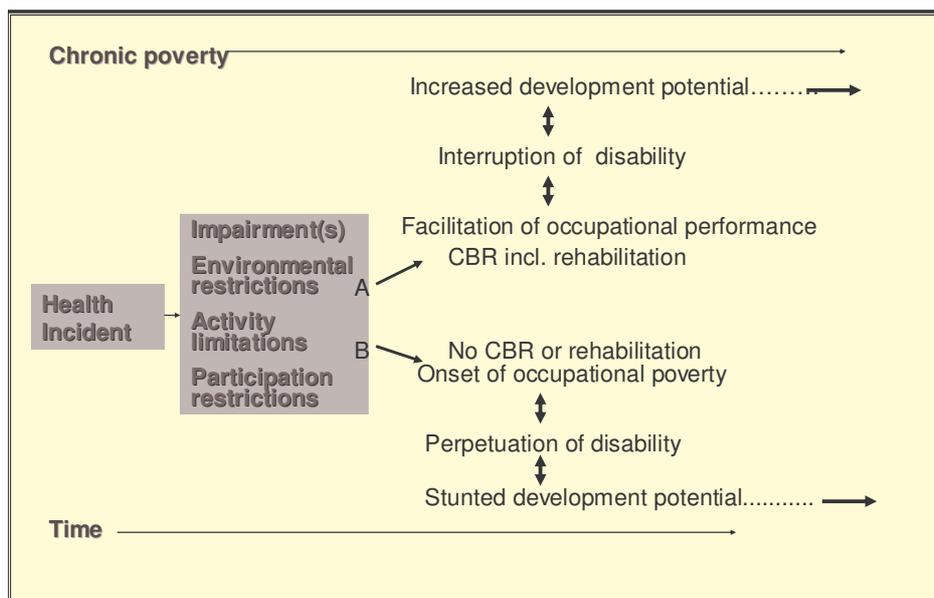


The Matrix reflects the principles of intersectoral collaboration for the attainment of inclusive social development and details the policy and implementation focus of each sector. The foundations of effective CBR programmes are a sound understanding of social health theory, community development and project management (Kronenberg, 2005; Hunt, 2005). Thinking of implementation we emphasise that the structure must

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accommodate the individual and his or her household. There are two pathways that a disabled, chronically poor person can follow after a serious health incident (see Figure 4 below). Pathway A unfolds a route to optimised development through CBR by addressing the occupational form and allowing for the facilitation of occupational performance. Pathway B occurs in the absence of intervention as is discussed above under the section entitled interruption of the PDO.

Figure 5 : Two possible poverty, disability and occupation routes



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A different trajectory: the process of change

A number of different facets covered in the paper so far can be drawn together around the matter of occupational performance and ways in which it can be facilitated⁴⁸. Changes in an individual's occupational repertoire can occur by making it possible for them to use their hitherto untapped potential, leading to new behaviours and learning. When abilities are recognised and matched to appropriate activity, a change in functioning and participation be achieved. Matching a person to occupation/s involves recognising existing environmental supports and constraints, the individual's capacity and the activity's demands. This process is applicable to anyone, including an individual who has a health condition or impairment, which has caused some limitation of performance component/s. Learning can be achieved (amongst others) through training, accommodation, adaptation and praxis.

- Training: a predictable and sequential cycle of coaching by taking action, examining what has been done, discovering how it could be improved, and repeating the cycle;
- Accommodation: a reading of the success of performance in order to make adjustments allowing for the best use of the individual's abilities without compromising the outcome of the performance; and

⁴⁸ Facilitation refers to a process of individual and group assistance and support which matches individual abilities to what people want and need to do and recognises and encourages their resourcefulness and agency

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- Adaptation: making the most of what the performer and the available resources have to offer, and modifying the process and the product if necessary.
- Praxis: the learner's conception of roles, tasks and activities, and how these are informed, directed and committed.

Responsibility for this process must lie with disabled people because they know best what they need to direct their own development. At the coalface of life in a remote rural village such as the ones at the centre of this paper the reality is somewhat different. Disabled people are not yet sufficiently mobilised or informed to claim access to the services they need and should rightfully have. Close collaboration between all stakeholders in line with the CBR approach would go a long way to changing the impasse at a systemic, structural level. The interruption of the disability/poverty cycle must however also happen at an individual and household level by enabling goodness of fit between the disabled doer, their occupations and the occupational form. Development is needed: between structural, multi-dimensional change on the one hand, and facilitation of the potential of the occupational human on the other. A lack of positive rural role models for disabled people could also contribute to discrimination and negative attitudes (Nkota, 2007),⁴⁹ something that the organisation Disabled People South Africa (2008) is trying to address. At present demands exceed person-power, but change can occur if connections are at least initiated between initiatives on the ground and umbrella constituencies.

⁴⁹ Mr Mandla Nkoto, Manager, Disabled People South Africa, East London office.

Conclusion

We have argued that poorly educated, unskilled and geographically isolated disabled people and their households have the capacity and agency, but not the resources and opportunity, to achieve what is necessary and desirable to them. They may also have difficulty imagining or hoping how things could change. Currently their participation and inclusion is restricted at a structural level by the discriminatory way society operates and by the absence or ineffective implementation of policy, rights based approaches and intersectoral services. These restrictions are particularly difficult to overcome, but not irreversible. At a personal level, while people continue to experience occupational deprivation, alienation and imbalance the consequence of these three inter-related dimensions will be occupational poverty. The dynamic relationship between poverty, disability and occupation suggests that the precursors and consequences of occupational poverty may be addressed by attending to and facilitating the goodness of fit between peoples' abilities, interests and agency and the demands of the roles, tasks and activities through which they meet their needs and give expression to their capabilities and capacities. Community based rehabilitation is an internationally recognised approach for advancing the inclusion, participation and equalisation of opportunities for disabled people. Occupational facilitation within this approach is likely to contribute substantively to development and, in particular, the health and well being of disabled people and their households. We pointed out that in order for human potential to unfold, it must be recognised, owned and elicited; matched to the task at hand and the context, and then guided and nurtured to overcome gaps in amenities, knowledge and skills. People cannot be empowered by some external, presumably more powerful and knowledgeable outsider. A participatory approach allows them to direct

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their own liberation and development path. Coaching, including education in any occupation is critical to the development of critical thinking, defining problems, knowing how to look for and apply solutions and developing performance skills. The occupational dimension creates the potential for fuller human development to be realised.

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