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The social life of questionnaires: Exploring respondents' understanding and interpretation of disability measures

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A thesis submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in fulfilment of the requirements for the degree of Doctor of Philosophy

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Declaration

I, Marguerite Schneider declare that this thesis is my own work. It is being submitted for the degree of Doctor of Philosophy in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.



_____

6 th November 2012
_____ day of _____,

To my daughters - Megan and Rosa

Learning is lifelong and fun!

Be inspired.

Abstract

Disability statistics are an important component of an informational base to monitor the needs and rights of people with disabilities within all spheres of life. The effective use of disability statistics is based on measures that are transparent and valid and where potential sources of sampling, interviewer or respondent error are clearly understood. This study investigates respondent sources of survey data error generated by three sets of existing questions on disability, as applied to adults in South Africa as a case study contributing to the growing work in this field at an international level. The questions are the Short and Extended sets of the Washington Group on Disability Statistics, and the Global Study on Ageing's (SAGE) health state description questions used by the World Health Organization.Disability is defined as the outcome of the interaction between a person's health condition or impairment, and the context in which he or she lives. The question evaluation considers: a) the wording, comparing asking about difficulties and disabilities; b) respondents' understanding and interpretations of whole questions; and c) the association between various life factors and the type and severity of functional profiles. The study uses a mixed methods design comprising focus groups, semi-structured interviews, in-depth interviews that tapped into the thinking behind respondents' answers to questions, and standard questionnaires. There were 21 focus groups located nationally, and 69 semi-structured interviews and ten detailed cognitive testing interviews at the Agincourt Health and Population Unit, located in a rural area in north eastern South Africa. The results provide insight into the performance of the questions, and, particularly, the need for revisions of the questions, potential respondent sources of error, and factors in people's lives that are associated with different response profiles. The analysis of wording shows that asking about 'difficulty' people have is a more inclusive and transparent measure than asking about disability. Analysis of respondents' understanding and interpretation of questions shows that questions on vision, hearing, walking and climbing, self-care and communication are well understood as intended, while the questions on remembering are misinterpreted in similar ways by a high number of respondents. Responses to non-traditional disability domains of pain, affect

(anxiety and depression) and fatigue (or problems with sleep) reflect predominantly people's reactions to living in adverse conditions. The measures provide a way to broaden the notion of who is counted as disabled because of functional limitations for statistical purposes, but the identity of being disabled remains a separate concern. The differences between measuring identity and functional status and the implications of these separate concepts is one area identified as an important focus of future research arising from this thesis. This thesis builds on existing knowledge by: providing strong evidence on the effect of asking about disability versus difficulty; illustrating the importance of question evaluation as part of validity testing and provide a further example to add to the growing literature on this approach; providing evidence on how responses to basic activity domains differ to those given to questions on feeling domains and the implications of this for how disability is understood in a low income and resources context of rural South Africa.

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Acronyms

- AHPU: Agincourt Health and Population Unit, based in north-east South Africa. The term is used interchangeably with Agincourt.
- CASM: Cognitive Assessment of Survey Methodology, an approach used to evaluate survey questions.
- DISTAT: The UN Statistical Division disability statistics database where countries submit their questions and data on disability.
- ICF: International Classification of Functioning, Disability and Health (WHO)
- SAGE: WHO's Global Study on Ageing
- StatsSA: Statistics South Africa, the national statistical office of South Africa.
- TFS: Total functioning score, a weighted sum of the individual domain scores on the SAGE questions.
- UNESCAP: The UN Economic and Social Commission for the Asia-Pacific region, where the cognitive and field testing of the WG Extended Set was conducted.
- WG: Washington Group on Disability Statistics, a UN City group focused on developing internationally comparable measures of disability.
- WHS: World Health Survey
- WHO: World Health Organization
- UN: United Nations
- UNCRPD or CRPD: UN Convention on the Rights of Persons with Disabilities

Note on terminology

I have worked in the field of disability studies for a number of years and have not yet found a consistently good argument for using one form of the following terminology over another. I thus use them interchangeably as suits the context.

- Person with disabilities
- People with disabilities
- Disabled person
- Disabled people

Chapter 1

Introduction

> Any theory of social ethics, and particularly any theory of justice, has to choose what we may call an 'informational basis'; that is, it has to decide what features of the world we have to concentrate on in judging the success and failure of a society and in assessing justice and injustice. In this context, it is particularly important to have a view on how an individual's advantage is to be assessed (Sen 2004:2, quotes in original)

Ensuring social justice requires a clear understanding of the factors that determine injustices and inequalities. In his lecture at the Disability and Development Conference hosted by the World Bank in December 2004, AmartyaSen argued the importance of including measures of disability and its impact within an overall assessment of social justice. By ignoring people with disabilities, or by considering them only as a 'special case', the wide diversity inherent in any society is negated, and information on the needs and rights of people with disabilities is missing. Disability statistics contribute to an informational base on these needs and rights.

Statistics, and specifically disability statistics in the context of my thesis, are useful only if they are accurate, and we understand what they reflect about people's lives. The accuracy of the statistics is determined by the performance of the measures used to generate the statistics. This thesis is about evaluating disability questions by testing the performance of these measures used in self-report surveys and I use data collected within the context of South Africa as a way to add to the growing body of work at an international level. These measures are only part of what is required for a full description of disability, but remain an important part.

Ideally, disability statistics should be useful for a wide range of users, including disability rights activists and public health specialists, as the specific focus of my study, but also all

governmentdepartments for developing disability inclusive policies and programmes. The focus of the thesis is on national and international statistics and not on information for clinical use, such as would be collected in a medical and rehabilitation context. Article 31 of the UN Convention on the Rights of Persons with Disabilities (CRPD) (United Nations - UN 2006: 23) affirms that 'States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention.' My aim in writing this thesis is to contribute evidence on how to collect 'appropriate statistical data'.

A disabled person is a person who experiences a loss of functioning in one or more domains, for example walking, hearing, cognition or communication, and who lives in an environment that does not effectively accommodate these functional or activity limitations (UN 2006; World Health Organization - WHO 2001). Disability measurement, consequently, includes measurement of functioning as one of the major components of disability. There are at least three different ways of measuring functioning. We can, firstly, observe people doing activities and rate the level of functioning; secondly, measure functioning objectivelyas is done when an audiologist measures hearing in a sound proof booth, ora physiotherapist measures muscle tone; or, thirdly, ask people to rate their own level of functioning. This thesis is about the last approach – asking people to report on their level of functioning.

The interaction of activity limitations and environmental barriers generates participation restrictions in a number of major life areas, such as limited education, lack of employment opportunities, limited access to basic services, and limited social inclusion. This understanding of disability is the basis of the International Classification of Functioning, Disability and Health also known as the ICF (WHO 2001) and is embodied in the United Nations Convention on the Rights of Persons with Disabilities (UN 2006). This is the framework on which disability measurement and statistics are based, as reflected in the World Health Organization's Disability Assessment Schedule (WHO-DAS II) and related surveys, such as the World Health Survey (WHS) and the Global Study on Ageing (SAGE)

(WHOn.d.), and the work of the Washington Group on Disability Statistics (Washington Group2008).Valid and reliable disability measurement is built on an understanding of the different components of disability that can and should be measured, ways of and difficulties in measuring these, and, most importantly for this thesis, how people report on these measures. Once we develop a goodunderstanding of these aspects and, more specifically, what lies behind people's responses, we can use the generated statistics more effectively, and predict potential sources of data error. Knowledge of what lies behind people's responses further enhances our understanding of disability as an experience.

There is a growing body of work on measuring disability. Notable examples of this work include the work carried out by Statistics Canada for the Participation and Activity Surveys in the late 1990s (Statistics Canada 2002), the indepth work carried out by the Australian Bureau of Statistics to develop their Census questions on disability (Black 2001), and the extensive questions evaluation work undertaken by the National Center for Health Statistics (NCHS) in the USA (Miller 2003; Miller and deMaio 2006; Miller, Mont, Maitland, Altman and Madans 2010). These are all examples of work in developed countries. My thesis continues this line of work in a developing or low resource context. In the next chapter, in section 2.4.2 on the history of disability statistics and measurement, I give a more detailed description of this international work and how my thesis contextualises itself as part of that growing body of work.

In this thesis, I aim to contribute to this literature by looking at the interface between the interviewer and respondent (when the questionnaire goes 'social') and, specifically, at the role of the respondent in giving responses to standard survey questions. I use data from South Africa as a case study, both at a national level (see chapter 4) and in a specific rural context in one area of South Africa (see Chapters 5 and 6) to contribute to the international debates and developments in this field.

In the language of survey methodology, questions or measures are traditionally assessed or evaluated in relation to their validity and reliability. Reliabilityusually involves a statistical evaluation of an instrument to determine whether the instrument is consistent, firstly, for each application; secondly, for application by different raters or observers; and, thirdly, in what it measures (Bruton, Conway & Holgate 2000). Reliability is not the focus of my thesis.

A precursor to determining reliability is establishing the validity of measures. Validity is a measure of the extent to which a test or series of questions measure what they are supposed to measure (Parry & Crossley 1950).To this day, this remains a useful description of the concept and is the meaning I use in this thesis: I assess, in a non-statistical manner, the performance of disability measures to determine whether they are measuring what they are designed to measure. I provide evidence on content, response process and face validity by analysing how people interpret and understand questions on disability, and the factors in their life contexts which may influence these responses.

The act of responding to a question is much more than a stimulus-response sequence (Willis 2005), but is, rather, a series of steps that occur simultaneously. These include: a) a reaction to the wording of a question, and b) a series of cognitive processes that occur at the point of responding (Miller&Willson 2009). Thesefirst two steps are informed or influenced by: c) a number of other factors within the person's life context, such as biography, age, education, sex, socio-economic status, values and opinions, and where they live.

The aim of this thesis is to look at these three aspects: the wording of questions (particularly the effect of using the term 'disabled' or 'disability' in the question); the concordance of the interpretation by respondents in relation to the intent of the question; and the association between the respondents' life context and their responses.

The research,descriptive in design, was conducted in South Africa. I used three sets of existing questions as the basis for investigating people's responses to these questions. Theseare the

Washington Group on Disability Statistics Short Set and Extended Sets (Washington Group, 2008; UNESCAP, 2010), and the World Health Organization's questions used in the Global Study on Ageing (SAGE) to measure health state descriptions[1] (Sankoh2010; Kowal et al 2010).

1.1 Measurement of disability in self-report surveys

This studyis aboutthe importance of testing people's understandings and interpretations of questions, specifically on disability, and their application of this understanding and interpretation in selecting a response option (amongst those presented), as is required in a survey context.The rise over the last two decades of theCognitive Assessment for Survey Methodology movement (CASM)(Willis 2008; seechapters 2 and 5 in this thesis) is a good example of the shift in survey methodology that occurred as understanding in the field of measurement developed, and methods for question evaluation became more central. Cognitive assessment or question evaluation is about asking respondents how they understand and interpret questions. This information is used to revise questions and in the analysis of the data collected (Miller & Willson 2009).

The field of disability measurement has shiftedfrom crude measures that ask about being 'deaf, blind, crippled or mentally retarded' or 'disabled', to measures reflecting the multi-dimensional nature of disability and its relevance to a much broader population than that identified by the former. This shift has been accompanied by efforts to develop measures that are reliable, valid and comparable across countries and contexts, as evidenced by the work of the Washington Group on Disability Statistics (Washington Group 2008), as one, albeit important, example. The anticipated outcome of these developments is a shift from the description of a small and marginalized sector of society to a broader description of population functioning,which acknowledges the universal nature

[1]Health state descriptions is the title of the section on functioning in the SAGE questionnaire. The meaning of this term is discussed further in Chapter 2.

of difficulties in functioning or activity limitations, which may or may not generate disability, depending on the interaction of these difficulties with contextual factors.

The disability measures evaluated in this study ask about difficulties in undertaking basic activities (seeing, hearing, mobility, self-care, communication, cognition), together with measures of outcome at a more complex level (education, employment, social inclusion). These outcomes are assessed in relation to a range of potentially facilitating or hindering environmental factors, such as the built environment, attitudes, services, and policies. These make up the different components of functioning and disability. Measures for these outcomes and related environmental factors are still in the process of being formulated and are not evaluated in this thesis.The crux lies in how all these interact to yield the outcomes. While processes of interaction are not themselvesmeasured, the measured outcomes provide some indication of the possible underlying processes. For example, if a person has limited ability to walk (basic activity) and is not working for pay (outcome of employment) because of an inaccessible built environment (environmental barriers), the assumed underlying process is the interaction between the barriers and the person's walking limitations.

Since the mid 20thcentury, the use of self-report surveys has become predominant as a method of collecting information in a range of disciplines (Willis, 2005), reflecting the 'historical ascendance of the subjective realm' (Converse 1987 cited in Willis 2005: 13), and an interest in understanding how individuals interpret their world. These surveys collect information on a group of people, in the case of sample surveys, or the whole population, in the case of censuses, to describe their various characteristics, such as their attitudes, their abilities or knowledge on various topics. This is done by asking a series of questions, the answers to which constitute the data (Scott & Morrison 2007). This information is important for accurate and efficient planning at, for example, a national level for policy development and, at more local levels, for the implementation of these policies. While I do not interrogate this further in this thesis, I do explore whether the information obtained from self-

report surveys is both accurate and clear in its intention and in the responses provided; in other words, I ask whether the questions are valid measures of disability.

One of the features of surveys is the 'systematic [measurement] ... of the same set of properties or variables, for each of a number of cases' (Scott & Morrison 2007: 233). This requires a standard set of questions, their application in interviews with a selected sample of respondents, data coding and capturing, and an analytical strategy. The analysis is based on the assumption that the data from different contexts and respondents are equivalent (equivalence of information) (Scott & Morrison 2007; Medina, Smith & Long 2009).Systematic measurement and equivalence across respondents is achieved, for the most part, if we can demonstrate that the understanding and interpretation of the questions is the same, and in concordance or congruent with the question intent, for the majority of the respondents.

With the increasing use of self-reporting in surveys, there has been a growing concern with sources of error in the data. These include a) errors of non-observation, related to coverage, sampling or non-responses; b) errors of observation related tointerviewer or respondent error; and c) post-observation errors related todata processing and interpretation (Willis 2005; Tourangeau 2003). The first and last types of error (non-observation and post-observation errors) are the domain of survey methodologists and statisticians and not of concern for this thesis. The second type of error (of observation) is the domain of questionnaire designers and is the area of concern here.Specifically, I focus on response errors,asking, 'Are we getting the right interpretation,as intended bya particular question?'.Response errors arise from 'the characteristics of questions, and of respondent processing of those questions, [which] may lead to incorrect answers'(Willis 2005: 14). Interviewer errors arise from misunderstanding (by the interviewer) of the questions they ask, reading them incorrectly, or marking the incorrect response. These latter errors have received little attention in the literature but are not the direct concern here. My focus in this thesis ison responseerrors, as signalled by respondents' mis- or 'out of scope' interpretations determined by their frame of

reference applied to answering questions. The use of the term error is with reference to statistical erroras noted when analysing survey data. The misinterpretations of respondents described in my study do not reflecterrors, as such, but rather interpretations that are not congruent or in concordance with the intended interpretation of the question designers. The process of question evaluation allows us to determine which of these misinterpretations lead to error in survey data. In order to achieve this we need to understand how different respondents respond across different contexts.

The last few decades have seen a shift, as described by Shakespeare (1996), from a relatively essentialist view of the world, where phenomena were seen as simple and linear, to a more nuanced view that recognisesthe complexity of phenomena such as identity, poverty, development, wellbeing, and disability. Recognising this complexity has important implications for developing measures for these phenomena. Thus, we find, for example, that the measurement of poverty has shifted over the last two decades from simple measures of income and wealth to more complex measures of interactive factors, such as income, expenditure, assets, nutritional status, and access to services and social networks and support.

A very real tension in disability measurement (as in other complexspheres) is to keep measures simple and easy to administer in a standard manner, while safeguarding the complexity and preventing the statistics from being interpreted as reductionist versions of the phenomenon.[2]The ideal of accurate and simple measures to represent a complex phenomenon is no simple task: the two could be construed as inherently contradictory.Reconciling this contradiction entails not only ensuring that the measures used are accurate, but also that those who use these measures and related statistics understand what is being measured and how to use and interpret the data. This

[2] The use of statistics to measure a complex phenomenon is very different to using an in-depth qualitative methodology to understand it. Both approaches are important but this thesis focuses on measuring complexity using statistics.

understanding is an important component of statistical literacy. The question evaluation undertaken in this study contributes to this understanding. A full description of disability for a population or country cannot be achieved by the use of a single statistic. Such a statistic must be understood in relation to the measures used, the component of disability being measured, and its relationship with the overall phenomenon of disability.

The strategy is not to deny the complexity, but also not topretend to measure something complex but using a limited and simplistic measure. In the face of this complexity, we, paradoxically, need simple, but not simplistic, measures. Measuring poverty by income alone is a simplistic measure, as is, for example, using Gross Domestic Product, or GDP, as a measure of wellbeing of a country's population (Eckersley 2008). Measuring different factors that contribute to the phenomenon of poverty leads to a range of simple measures that, together, provide more valid, reliable and comparable data on poverty. This is true also for disability.

1.2 Disability and wellbeing

The terminology around disability is fraught with confusion and multiple meanings. The definition Iuse is a broad and generic one provided by the International Classification of Functioning, Disability and Health (ICF) (WHO 2001), but I also draw from the work of other theorists working in the field of disability (see Masala and Petretto 2008 for an overview). The ICF defines disability as a complex and multidimensional phenomenon and the outcome of a complex interaction. The elements of the interaction are a health condition or impairment, a person with that condition, including social and demographic factors such as age, sex, personality, educational achievement and other individual factors, and external factors, such as the built and natural environment, support from and attitudes of others, and policies, systems and services. The outcome of the interaction is functioning or disability. These are presented by the ICF as two sides of the same coin: disability occurs when the person has difficulty in functioning. The health condition is the starting point but is not disability. Health conditions include injuries, traumas, chronic or acute illnesses, and may or may not require

ongoing health care. Health conditions lead to physical, sensory, cognitive or mental health impairments. Disability arises as a consequence of living with the health condition. Forexample, a person has rheumatoid arthritis, a health condition, which interacts with the context in which that person lives, including access to health care, nature of the transport, and support of others. The outcome of that interaction will determine whether the person experiences disability or functioning, in the ICF sense of these terms. A positive context (good access to health care, accessible transport and positive support and attitudes) will minimize the detrimental effects of rheumatoid arthritis and enhance functioning, while the converse will cause disability. These two sides of the coin can also be identified as two ends of a continuum – from full functioning to full disability. All members of a population can be situated along this continuum, thereby reinforcing the universality of functioning, rather than the categorical notion of disabled versus non-disabled, as discussed below and in Chapter 2 in more detail.

Wellbeing is something we strive to achieve as individuals and nationally, where governments aim to ensure the wellbeing of their populations. Wellbeing is a broad notion and not always clearly defined but, for purposes of this introduction, I define it as a broad overarching notion of achieving development of the individual into a fulfilled member of society. It comprises a number of components – objective and subjective — all interacting to create wellbeing or illbeing, when things go wrong (Cummins 1997;Manderson 2005; Sen 1999a). In this thesis, I am concerned with wellbeing in as much asresponses to questions on disability are shaped by people's sense of wellbeing. Beyond this thesis, we can look at how functional difficulties can affect people's wellbeing.

1.3 Disability measures

As stated earlier, I do notdevelopmeasures of disability, but evaluate existing measures that fit the current understanding of disability. These are the Washington Group Short Set (Washington Group 2008) and the World Health Organization's set of questions used in the Study on Global Ageing

(SAGE study) (Sankoh 2010; Kowal et al. 2010). I evaluate these questions in terms of their performance inone rural area, in detail, and nationally in South Africa in less detail. The WG Short and Extended sets were developed in response to a growing need for internationally comparable and valid measures of disability (Washington Group 2008), while the SAGE questions are based on the World Health Organization's Disability Assessment Schedule (WHO-DAS II) (Üstün et al. 2010; Garin et al. 2010), an instrument measuring disability and based on the International Classification of Functioning, Disability and Health (ICF) (WHO 2001). The decision to evaluate these measures is based on them being typical of the current way of understanding measurement of disability coupled with two opportunities made available to me to pursue this evaluation process. The first opportunity was an exercise undertaken in 2006 by Statistics South Africa to develop a disability schedule for the South African Census of 2011 and I was given the task of planning and executing this research. The second opportunity was the possibility for doing some additional question evaluation work as part of the WHO's Study on Global Ageing (SAGE) undertaken by the Agincourt Health and Population Unit in rural Mpumalanga Province in South Africa. I describe these in more detail in later chapters. The latter opportunity was furthermore, related to an international project collecting cognitive testing interview data on the WG Extended Set from around 10 countries.

Measures used for population statistics are different to clinical assessment measures. Clinical measures require time and detail to obtain a comprehensive assessment of a person's functional status for purposes of developing an appropriate individual medical and rehabilitation intervention programme. Survey measures of disability are not about assessing the detailed nature of a person's functional status, but about identifying the presence or absence of difficulties or disability. They do aim to provide some information on type and severity of disability or difficulty. However, this information is not for purposes of planning individual intervention programmes, but to establish profiles of functioning at a population level that can be analyzed in relation to other variables typically collected at population level. This information is useful for understanding population trends

and monitoring population level interventions. The clinical and survey platforms for collecting information are complementary and should be compatible with each other, for example, using the same underlying framework for describing disability.

1.4 Disabled and non-disabled people

This study is not about disabled people as traditionally understood – people in wheelchairs, deaf people, blind people, or intellectually disabled people. I do not identify disabled people and describe their functioning and wellbeing. I look at responses to questions that are said to measure disability, and from these, create a series of profiles that assist us in defining who counts as 'disabled' or 'non-disabled'[3]. This binary categorization is not a set point, but can be done in a number of different ways using different categorizations of the data and different counts. For example, as discussed later, decisions are made on whether to include only people with 'a lot of difficulty' or 'unable to do' in the category 'disabled', or to also include people with 'some difficulty' in this category. Understanding how questions are interpreted is one part of the evidence required to decide how to place cutoff points on a continuum.

1.5 What is the social life of a questionnaire?

The title of my thesis captures the notion of applying a set of questions (a questionnaire) in a context that would typically be used in self-report surveys;in other words, moving out of the 'laboratory' and being exposed to people who respond about themselves. This opens the questionnaire to broad interpretations, many not anticipated by those writing the questions. My experience of questionnaire development is that, in phrasing a question, one is clear on its intent. However, that clarity is limited to one's own life context. In responding to the questions, a 'real' and, often, 'naive' respondent bringshis or her own life context and perspectives to bear, generating a range of

[3] I use inverted commas for 'disabled' and 'non-disabled' when referring to the identification or counting in based on the measures I am evaluating.

different interpretations of the question, and providing unexpected responses. This is particularly the case when the life contexts of question developers differ significantly from respondents in terms of education and socio-economic status (Miller 2003; Loosveldt 1997). Some of these interpretations will be congruent with intended meaning, and others not. This is when the questionnaire starts its social life and when sources of respondent error emerge. The reciprocal nature of social relations is captured in the use of the information on interpretations to revise and improve a questionnaire. The title refers to questionnaires in the plural, as the methodology used is relevant for any type of self-report survey, not only in the field of disability.

In conclusion, I take as a given in my study the use of self-report surveys as a valid form of data collection, and the use of questions on basic activities as the current status of disability measures.

1.6 The context of South Africa

South Africa is a low and middle income country that has a high level of inequality ranging from first world, highly developed infrastructure through to cramped tin shacks in informal settlements, and lack of any decent services in poor rural areas. The democratic government elected in 1994 has enacted a number of important pieces of legislation that stand out as exemplary with regard to the rights of many minority groups, including people with disabilities. These range from the overarching South African Constitution, through to a range of more specific pieces of legislation, such as the Employment Equity Act (see www.gov.za). South Africa is a signatory to the UN Convention on the Rights of Persons with Disabilities and was one of the first countries to ratify the Convention (UN 2006).

In addition, South Africa has a strong social assistance programme that includes a cash grant for people eligibile on the basis of disability both for children (Care Dependency Grant) and adults (Disability Grant) (see www.dsd.gov.za). Other social assistance grants include the Child Support Grant, Foster Care Grant and Old Age pension (see www.dsd.gov.za). South Africa has a strong

legislative and social security system, but remains a poor implementer of these good policies and programmes (Swartz & Schneider 2006).

According to Statistics South Africa (2012), the total population of South Africa is just over 51 million, with the most populated province being Gauteng, the economic hub of the country. Just under 80 percent of the population is Black, and nine percent White. The data collection for my thesis was predominantly among the poorer and less educated sectors of the population for all the data collection (focus groups and interviews), and among a Black, poor, low educated and rural population for the interviews in the Agincourt area, as I describe in more detail in Chapter 3. These are typically the respondents who show the most variation in their interpretation of self–report survey questions relative to the intent of the question developers (Miller 2003), and hence the right population to target in this thesis.

Education levels are generally increasing in South Africa, but the proportion of the population with matric remains under 30 percent of the population 20 years and older, and nine percent of the population have no formal education. Mpumalanga, the province where Agincourt is located, has the second highest provincial rate of no formal education (14%), and third highest rate of unemployment (42%), when including those people unemployed and who have stopped looking for work. This figure is 40 percent for the whole of South Africa.

1.7 Structure of the thesis

In Chapter 2, I review the literature on and set out a conceptual framework for understanding disability, its measurement and its relationship to wellbeing and health. This section concludes with the aims and objectives of my study and the specific questions I asked.

In Chapter 3, I describeand justify using the mixed methods approach to explore questionnaire response, and contextualise the different data sources used in the analysis. I conclude the chapter by setting out my analytical strategy.

I present the findings in chapters 4, 5 and 6 together with a discussion on the implications of these findings integrated into each chapter. I start in Chapter 4 withthe effect of question wordingwith reference to asking about ‘disability’ and ‘difficulty’. In Chapter 5, I undertake an evaluation analysis on the WG Extended Set questions, focusing on the understanding and interpretation of these by ten respondents. In Chapter 6, I present the different profiles generated from the responses to the questions by 69 respondents, and their non-statistical associations with a range of life context factors. Profiles I consider are the severity of the difficulty and the type of difficulty reported.

In Chapter 7, I comment on the overall performance of the questions evaluated, discuss the implications for measurement of disability and our understanding of disability. I end that chapter with a discussion on the difference between the measurement of functional status and disability identity.

In Chapter 8, I present the conclusions and recommendationsof my study, and set out the specific contribution and limitations of this thesis, with suggestions for further advancing this field of study.

Chapter 2

Literature review

Given the focus of my thesis on how questions used to measure disability are understood by respondents in self-report surveys, this chapter focuses on the following: defining disability and implications of definitions for measurement; disability measurement; approaches to question evaluation in the field of survey methodology; and, potential factors, such as health and wellbeing, that influence respondents in how they answer questions. While I cover all of these topics in this chapter, the order is not as presented above.

The theoretical concerns for this thesis are the current understanding and measurement of disability. This understanding provides the conceptual framework for assessing the performance of disability measures. The thesis falls within the field of survey methodology, and, specifically, focuses on the role of respondents. Respondents are key informants on their own lives (Miller & Willson 2009), and, as such, introduce a number of factors that influence the responses they give. Accurate measures of disability are obtained when these respondent factors lead to question responses which are congruent with the intent of the question as determined by the question designers. The notion of error in survey data is recognition that this congruency is never fully achieved. The aim of question evaluation is to understand the sources of error, as far as possible.

2.1Conceptualizing disability

In this section, I provide a review of some of the major shifts in how disability has and is understood. This information is important because of the close relationship between understanding and defining disability and the measures these spawn.

The term disabled or disability has taken on many meanings. Nelson Mandela (1993) referred to 'those who have been *disabled* and brutalized by apartheid' (my emphasis); a radio talk show host

talks of school boys being 'disabled' by a criminal record early in life (Jenny Cwrys-Williams 702 Radio, Johannesburg, 4June, 2009). Disability activists talk about being disabled by society. The use of the term in these contexts and others has, as a common feature, the notion of disadvantage. However, the starting point of this disadvantage is different in the different contexts – a socio-political system that excludes one group from privileges enjoyed by another on the basis of race, a discriminatory attitude to someone for some wrongs committed, and a health condition. This thesis is concerned with the last meaning or context of disadvantage – health-related disadvantage.[4]

The use of the term 'disability' tends to have a much narrower connotation in everyday parlance – activity limitations or difficulties doing various activities. This is the term's use in the World Health Organization's 1980 Classification of Impairment, Disability and Handicap (ICIDH) (WHO 1980), which was the precursor to the International Classification of Functioning, Disability and Health (ICF)(WHO 2001). The ICF shifted the use of 'disability' to an umbrella notion as the opposite of functioning. Disability is the outcome of an interaction between a person with a health condition and that person's life context (WHO 2001; UN 2006). This definition combines features within the individual with features external to the individual. This understanding of disability is the culmination of an ongoing historical process that may yet generate further changes. This process has generated a number of disability models, including the individual or medical model, the charity model, the social model and the human rights model. While the ICF has generated much debate and criticism, it provides, in my opinion, a succinct and comprehensive model and framework of the different components of disability. The model presented by the ICF is a biopsychosocial model and it is discussed in more detail below. The understanding the components that make up a phenomenon is crucial if measures of that phenomenon are to reflect the construct they intend to measure.

[4] The juxtaposition of health and disability does not imply in any way that health and disability are synonymous or that they are opposites, but it does imply that they are closely related.

Altman (2001) and Masala and Petretto (2008) provide a comprehensive review of different disability models from the 1960s to the late 1990s. They show how these models shifted from a narrow focus on the individual as the locus of the problem, to highlighting the importance of environmental factors in creating significant barriers for individuals with impairments.Historically, disability was understood as a characteristic of an individual that categorized that individual as, typically, 'deaf, blind, crippled or mentally retarded' (Barnes and Mercer 2004; UNStatistical Division - UNSD n.d.). These categorical identities are applied in a stereotypical manner, with little consideration of individual differences within each category. For example, blind people were, and continue to be, guided to careers as telephonists or lawyers, as these are seen as accommodating blindness. Little effort is made to understand the nuances of individual achievement or ability within a group of people thus crudely classified. In this way, the individual is lost – he or she becomes his or her disability, and not a person with individual characteristicsand related activity limitations (or a profile of functioning across different domains with full functioning in some and full disability in others). Nor does this individual, medical or categorical perspective separate out the person's individual capacity from the role of environmental barriers and related outcomes. Their identity is set foremost by their disability. Measures based on this categorical perspective yield low estimates of disability (UNSD n.d.), and perpetuate the view of disability as a small group of marginalized people- 'the disabled', few in numbers, andexcluded from mainstream society.

Furthermore, this categorical perspective gives little or no acknowledgement of the role of the environment in determining wellbeing. This lack of recognition endorses the narrow individual, what has been termed the 'medical model' view of disability. This model places the locus of the problem and focus of intervention within the individual (Oliver 1990; Barnes and Mercer 2004; Schneidert[5], Hurst, Miller & Ustün 2003; WHO 2011). Reactions to this perspective of disability led to what has

[5] This article was published with the incorrect spelling of Schneider as Schneidert.

been termed the 'social model' (Oliver 1990; Barnes & Mercer 2004). The social model sets the external environment, including the built, social and attitudinal environments, as the locus of the problem and the focus of interventions. This model swung to the opposite extreme, some writers have argued, by ignoring the individual (Thomas 2004; Kristiansen, Vehmas& Shakespeare 2009) and acknowledging only the predominant role of the environment in generating disadvantage. This approach denies the individual's agency in their own wellbeing (Kristiansen et al. 2009; Sen 1999a). As humans, we all combine what we bring as individuals and what the world around us contributes. This social model perspective retains, in my opinion, the notion of a small, marginalized group within society, albeit with the strong recognition of the need to change this status, contrary to the medical model.

The two extremes of the medical or individual and the social model, while important in understanding disability politics and growing awareness on disability, do not reflect different phenomena so much as different components of disability. The medical model focuses on individual characteristics, and the social model focuses on environmental factors. The ICF,[6] as represented in Figure 1, embodies both the individual and social model perspective, and allows us to describeboth what a person can and cannot do, and incorporateskey elements that we know to be important in describing and measuring disability. The ICF provides an individual profile focusing on both abilities and disabilities of an individual, and their interactionwith the context or environmental factors of the person's life. This profile allows decisions to be made on where the interventions must focus – the individual or the environment.

[6] There has been a significant amount of literature critically reviewing the ICF. This is acknowledged and the use of the ICF as a framework for describing disability is used, nevertheless, as the most developed framework available currently for describing the components of disability and process of disablement. See Bickenbach, Chatterji, Badley, & Üstün (1999) for further discussion on the merits and demerits of the ICF.

The components of disability described in the ICF include: a) the health condition and b) the context of the person (including both individual and external environmental factors)[7] that interact to yield the outcome of functioning (or disability, if there are difficulties in functioning). Functioning is described at three levels – body function and structure, person or activity, and societal level or participation. Problems (or disability) are described, respectively, as impairments (body level), activity limitations (person level) and participation restrictions (societal level). The ICF model, presented in Figure 1, indicates that these three outcome levels are influenced by environment and personal factors. The circled component 'Activities' denotes the component measured in the focus of questions I evaluate in my thesis, although with some overlap onto impairments of body functions (hence the left-stretched oval).

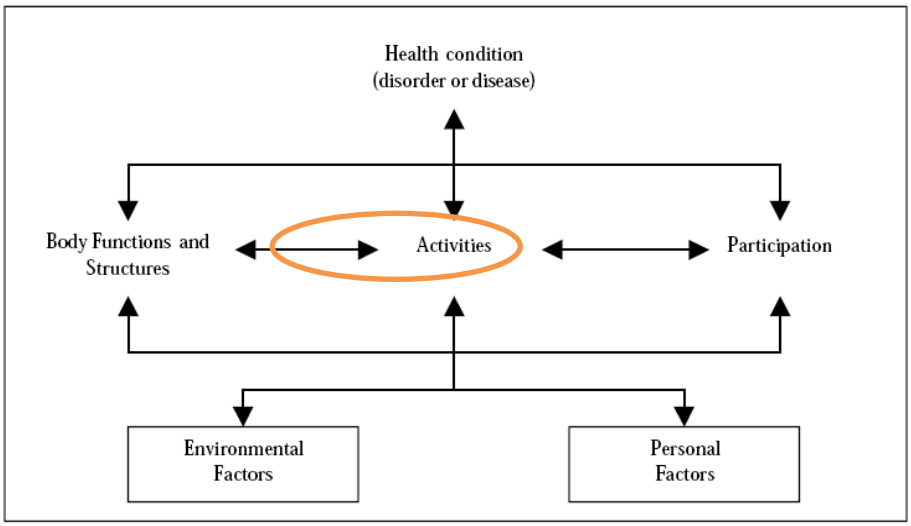


Figure 1: Interaction of components in the International Classification of Functioning, Disability and Health (adapted from WHO 2001:18)

Two examples explain the interaction model of the ICF. A person with a spinal cord injury (health condition) will experience muscle weakness (impairment of body function) and an inability to walk (activity limitation in mobility). If there are no services (environmental factor) to provide

[7] The notion of environment is defined broadly by the ICF to include the physical and built environment, support from and attitudes of others, and policy, systems and services (WHO 2001).

rehabilitation and without a wheelchair (environmental factor), the person is unable to get around and remains isolated in herhome. In addition, if that person is provided with a wheelchair and cannot find employment, because she is a wheelchair user (attitudinal barrier) or because of an inaccessible workplace (physical barrier), she experiences further disadvantage - unemployment and related economic and social exclusion. Similarly, a child born deaf (an impairment), in an area with no early identification and intervention services (lack of services as an environmental barrier), is disadvantaged through lack of an effective education (environmental barrier), with significant repercussions in adulthood.

In summary, the ICF provides a framework to describe the functional status,as disability or functioning, of a person across a number of different domains. Disability is only fully described when all these aspects have been considered. Therefore, measurement of disability in self-report surveys needs to consider all of these aspects to provide a comprehensive description of disability.The measures of disability used in this thesis are based on the ICF. The current measures focus on activity (see circled component in figure 1)for reasons elaborated below. While, in my opinion, the ICF provides a very useful model to frame measurement of disability, I also understand that it may have limitations, described, for example, by du Bois and Trani (2009), for 'policy design, programme definition, development practice, promotion of participation and identification of barriers to inclusion'. It is part of a set of tools available to researchers, but should not be viewed as being the only tool.

The ICF has the same classification for both Activity and Participation, which includes nine chapters comprising nine domains of functioning. These are, in order of appearance in the ICF: Learning and Applying Knowledge; General Tasks and Demands; Communication; Mobility; Self-care; Domestic Life; Interpersonal Interactions and Relationships; Major Life Areas; and Community, Social and Civic Life (WHO 2001). Some of the domains of functioning in earlier chapters are building blocks for later domains of functioning. For example, the ability to use sensory information from seeing and hearing,

being able to walk, communicate, remember and concentrate are all important for the more complex domains of learning, being employed, and maintaining social interactions and relationships. While the ICF does not provide any hierarchical ordering of the nine chapters, the consideration of such a hierarchy is useful for understanding measurement of disability, where it is easier to measure basic domains of functioning than the more complex ones. The more complex the domains, the more difficult it is to establish cross country comparability in measures, as different geographical, linguistic and cultural factors have to be taken into account. For example, asking about difficulties in working or staying alone at home generate responses that include difficulties related to factors other than health and disability, such as a lack of job opportunities, and cultural practices or safety concerns that do not allow a woman to stay alone. This is the one of the reason for focusing, in my thesis, on the basic rather than complex domains of functioning in the measurement.[8]This does not mean that measures of complex domains and environmental factors are not needed. On the contrary, they are crucial for a full description of disability, but require more time and research to be developed as effective measures. This work is ongoing.

An added strength of the ICF is that it moves beyond the perspective of disabled people as marginalized in society, and highlights the universal nature of disability within the life course. We all experience some degree of difficulty in functioning for shorter or longer periods in our lives. Thus, disability is about everyone. This brings a notable shift in perspectives and opens up the identification of disability within a wider group of people – the whole population. The presence of functional limitations does not always lead to disadvantage. A person with a minor limp has a functional limitation in walking, but this may not result in any disadvantage in major life areas of education, employment and social inclusion. The ICF allows for a continuum from full functioning to full disability. Different cutoff points can be set on this continuum to determine at which point a

[8] As I discuss later, another important reason is that the measures developed and tested so far have focused on basic activities, in the work of the Washington Group, predominantly but not exclusively.

person can be considered or counted in (for statistical purposes) as disabled. The selection of the cutoff point will be made according to the purpose for which it is required. For purposes of understanding disadvantage, the cutoff point would be towards full disability, while for establishing the proportion of a population who would benefit from, for example, fully accessible buildings and transport, a cutoff point close to full functioning would be required.The measure of population functioning is differentto measuring identity status as a disabled and marginalized member of society. These two different perspectives on disability require different measures. The historically dominant categorical measures, while perpetuating marginalization of disabled people, should not necessarily be seen as a good measure of identity status, as I explore in this thesis.

One's identity as disabled stems from being different and having difficulties, or functioning in a different way. This difference is perceived and understood by others as being a marker for stigma and disadvantage, leading to disabled people being seen as human beings but not counting as persons or not having full personhood (Ikäheimo 2009). Ikäheimo (2009:79) discussed the features of personhood and makes the distinction between institutional and interpersonal statuses that comprise personhood. The 'institutional status concept of personhood' refers to society's obligations towards others in relation to, for example, the right to life. The 'interpersonal status concept of personhood' refers to 'being seen as a person by others'. This latter notion is about attitudes that lead to people identifying as 'we' and 'them' or 'us' and 'others'. Seeing a person as worthy of being loved, respected and valued as a contributing member of 'us' (Ikäheimo 2009) are those features that include someone as being 'us' rather than 'them'. If a person is denied these features because of being different in functioning, he or she is not included in the 'usnon-disabled' group. This leads disabled people to identify as a different 'us' within the ambit of the disability rights movement – 'us disabled people'. Ikäheimo goes on to discuss how a disabled person is not seen 'as a person who has authority, a seriously taken claim to happiness, and/or something gratitude-worthy to contribute' (2009:84), and, hence, is socially excluded and relegated to 'them'.Ikäheimowas writing

in 2009 about the current period, suggesting that, in many ways, we have not changed much in our views and treatment of disability since the early 1900s (Humphries & Gordon 1992).

The historical base for the stigmatization and marginalization of people with disabilities is well described by historians and literary critics, amongst others. The descriptions provided by writers such as Douglas Baynton (2001), Rosemarie Garland-Thomson (1997) and Mike Miles (2000) show clearly that disability has consistently been used as an outsider category, a deviance from the norm, a state one does not one want to be in. Miles writes about these trends being evident in religious writings already 2500 years ago, and Baynton provides strong evidence of the role of disability in justifying inequalities in American history continuing into the 21st century. Baynton analyzes how the use of a range of terms denoting physical or mental weakness, deformity or ill health were used to justify race-based segregation and slavery, oppression of women and marginalization of disabled people. The human rights movements for black and women's empowerment have gone a long way to address many of these negative attitudes. The disability rights movement started later than both of these movements – inthe late 1970s (United Nations 2003-04), and continues today as an influential body in national and international politics as evidenced by bringing into force the UN Convention on the Rights of Persons with Disabilities (UN 2006).

The role of statistics, as I understand it, includes to provide statistical descriptions and documentation of experiences of groups, both dominant and marginalized, and ensure that these are visible in mainstream statistics. Thus, for example, disaggregation of survey data by population groups in South Africa remains necessary until there are less population based differences in life outcomes. The gendered analysis of survey data allows, in a similar way, to understand the different conditions of men and women at a population level, and is a given for any analysis of survey datanowadays. The aim, with disability statistics, is to develop measures that are robust and valid and allow for mainstreaming of disability within statistics, by ensuring that we understand what these measures and related statistics mean. I have often seen surveys include measures of disability,

but then relegate the analysis to a separate chapter, when the gender, population group, age, and geographical location analyses are all integrated. This practice and use of the categorical measuresdescribed above, reinforce this 'them' and 'us' approach and encourage the continued marginalization of people identified by these categories.

2.3 Disability, wellbeing and health

In this section, I highlight some key aspects of the relationship between disability, wellbeing and health. These underpin our understanding of disability and provides insights into how wellbeing and health are affected by disability, and disability affected by wellbeing and health. These relationships are useful in revealing potential explanations for how these factors and their interrelationships affect how people answer self-report survey questions on disability.

The revision of the ICIDH and adoption of the ICF followed the publication of the World Bank's World Development Report of 1990, which set out the Human Development Index based on Sen's Capability Approach (Sen 2000; Chiappero-Martinetti 2000). There are, consequently, many similarities between the Capability Approach and its framework for describing and explaining development and wellbeing, and the description of disability and the disablement process. Both phenomena introduce the notion of complex system comprising many different components that interact in multidimensional ways to generate outcomes of development, for the Capability Approach, and disability and the disablement process.

Sen's (2000; 1999a) Capability Approach describes development (achieving wellbeing) as requiring inputs or resources that the individual uses to achieve 'beings' and 'doings'. These in turn determine the extent of a person's capabilities or capability set. The individual's choice of which capabilities to realize is, in part, determined by the size of the capability set, as well as the constraints and opportunities presented to the individual in their external environment, including food, safety, housing and means to sustain him or herself, and within their own personal resources, including age,

health, sex, education and personality. The outcome is a range of functionings[9] or realized capabilities. The larger the capability set, the more choice a person has; the greater the number of constraints, internal or external, the lower the choice. The functionings that are realized, in turn influence the inputs and resources that determine individual development and wellbeing. And so the cycle continues. People with limited resources will develop a limited capability set, and be constrained in their realized functionings, in part by this limited capability set. They may also be further constrained in their functionings by the factors that led to the limited capability set in the first place; for example, poverty. Someone with a large capability set may still have a small set of realized functionings, if constraints arise, such as loss of employment or a serious injury or illness. Sen refers to development as achieving wellbeing (1999a). Disability, as described in the preceding section, has its own pathway, but plays a role as an input factor into a person's development and wellbeing. Health is a basic resource for wellbeing, as I discuss below, and is closely related to disability, as I raised above in defining disability.

2.3.1 Wellbeing

Wellbeing is seen as an essential emerging concept in the study of a range of phenomena, for example, poverty and health (Clark & Gough 2005). The notion, and related measurement, of wellbeing is high on the international development agenda (Tiwari 2009; Gough, McGregor& Camfield 2007), but remains a changing and elusive concept (Clark & Gough 2005; Gasper 2007). In their extensive review and use of the concept, Gough and colleagues (2006: 5) conclude that, while there is no consensus on its meaning, wellbeing is simply 'a useful umbrella term, beneath which a variety of related ideas and concepts can shelter'.

[9] Although related, the term 'functionings' as used by Sen should not be confused with 'functioning' used in the sense of the ICF and functional status.

For purposes of this thesis, I am using quality of life and wellbeing interchangeably, while recognising that a detailed investigation of each may reveal important distinctions. My readings of the literature suggest that there is confusion as to their differences and a common interchangeable use of the two terms. Ruta, Camfield and Donaldson (2006), for example, start their paper on developing a working definition of quality of life, by stating that much work in the field is found under the rubric of both wellbeing and quality of life. Ruta and his colleagues (2006: 11), in their efforts to develop a workable definition, define quality of life as 'the gap between what a person is capable of doing and being, and what they would like to do and be'. Uyan-Semerci (2007) focuses on the outcome or what a person succeeds in doing or being (2007). Sen refers to quality of life as 'good living' (Sen 1999b, 2004). Many texts about wellbeing avoid providing a definition as such, not unlike the UN Convention on the Rights of Persons with Disabilities (CRPD) that avoids providing a definition of disability. Rather, in the CRPD and in literature on wellbeing, a description of the phenomenon is provided. Sen describes wellbeing as being 'concerned with a person's achievement: how "well" is his or her "being"?' (1999b: 3, quotes in original).

Despite this lack of definition, it is accepted that wellbeing comprises a number of components and dimensions. The different components of wellbeing described by different authors reflect their own theoretical perspectives. The emerging consensus, nevertheless, is that wellbeing comprises both objective and subjective components (Gough et al. 2006; Clark & Gough 2005; Tiwari 2009; Easterlin 2003). There are different types of wellbeing referred to in the literature, such as health wellbeing, material wellbeing, emotional wellbeing and spiritual wellbeing, or, even more specifically, income wellbeing and housing wellbeing, as reviewed in an edited book by Manderson (2005) entitled 'Rethinking Wellbeing'.

I am using the notion of wellbeing to indicate a person's sense of living a 'good life' physically and mentally, and expressing this wellbeing as a positive degree of satisfaction. It is an individual

attribute and described by an individual about themselves, although community wellbeing is emerging as another component of overall wellbeing (Wiseman and Brasher 2008).

As there are many different definitions of wellbeing, so there are different lists or sets of components that make up this phenomenon. If one is to consider the impact of a person's life context on their responses to questions on disability, it is important to understand what this life context consists of, and if it generates wellbeing or illbeing. Different theories of wellbeing provide different, but often overlapping, components comprising overall wellbeing. Examples of these are provided by Nussbaum (2005), Cummins (1997), Doyal and Gough (1991 cited in Clark and Gough 2005), and Maslow (1987).

These authors, working across a range of different disciplines and theories, retain a common list of these components, including nourishment, housing, lack of illness, safety, agency and autonomy (specifically mentioned by Clark and Gough 2005) and a 'feeling of being connected' and 'belonging, esteem, and self actualization' (specifically mentioned by Maslow1987:22).

The understanding of wellbeing provides a useful framework to highlight the factors that are important to consider when investigating the performance of disability measures, and specifically what life context factors may be influencing people's responses to these measures. I now turn to discussing some of the factors that determine wellbeing.

The wellbeing and quality of life literature (for example, Møller and Saris 2001; Cattell 2001; Patel, Abas, Broadhead, Todd & Reeler 2001; Surtees & Wainwright 2007) describes three main types of factors related to wellbeing: firstly, external factors, such as housing, education, geography, and poverty; secondly, internal factors, such as sex, age, presence of health condition and its chronicity, and personality; and, thirdly, social factors, such as networks, social capital, and social support. In addition, Wiseman and Brasher (2008) describe four social and economic determinants of mental health: freedom from violence, freedom from discrimination, social inclusion and connectedness,

and economic participation and security. These may be important to consider in understanding how people formulate their responses to questions on functioning and disability.

2.3.2. Health and wellbeing

Cattell (2001: 1502) found that health and wellbeing were influenced by social capital as 'a resource produced when people cooperate for mutual benefit,' including formal and informal social networks, and trust. She concludes that 'a wide array of influences interacting in complex relationships affect health' (Cattell 2001: 1512). Some particular factors noted in her study included social consciousness, membership of organisations, diversity of the networks that people have access to and, through these, access to a wide range of resources. Surtees & Wainwright (2007: 95) concur on the association of social adversity and chronic diseases, and suggest 'including a collection of comprehensive social adversity data within chronic disease epidemiological settings ... for aiding understanding of individual differences in physical disease aetiology.' This conclusion underpins the importance not only of collecting information on social adversities to understand chronic illness, but to also consider these in understanding how people report on the consequences of living with chronic illness, these consequences including functional limitations measured as disability.

An important component of health and wellbeing is mental health, an important aspect of public health (Lund et al 2011; Moussavi et al 2007; Aidoo& Harpham 2001; Patel & Kleinman 2003; Patel, Abas, Broadhead, Todd & Reeler 2001; Havenaar, Geerlings, Vivian, Collinson& Robertson 2008), but largely ignored in general debates on development and poverty (Lund et al 2011; Miranda & Patel 2005). Of particular interest are common mental health disorders, such as anxiety and depression (Patel & Kleinman 2003; Havenaar et al 2008). There is a close connection between poverty, social stressors, and depression (Patel et al 2001; Patel & Kleinman 2003; Aidoo&Harpham 2001).

These authors identify insecurity and hopelessness, rapid social change, being at risk for experiencing violence, and physical illness as important factors in understanding the relationship

between poverty and common mental health disorders (Patel & Kleinman 2003). Cattell's study (2001) was based in housing estates in East London, UK, and showed how people see health as being related to the death of loved ones, concern over not having enough resources to meet one's needs and getting into debt. She raises another common thread in people's narratives around health – the importance of social support for 'when things go wrong, or being able to talk about problems for example' (Cattell 2001: 1511).

For my purposes, two potential sources or causal pathways of anxiety and depression can be noted – firstly, a clinically diagnosable chemical or related disorder inherent in the individual, that results in feelings of anxiety or depression that seem out of proportion to the context; and secondly, feelings of anxiety and depression arising from a person's adverse life context. The different sources are important to differentiate as they should generate different intervention pathways. For internally generated feelings, an individually focused intervention may be suitable, including medication or psychotherapy. For externally generated feelings, the required intervention must be broad and beyond the individual, and including social assistance, poverty reduction, increasing social support and improved education. This leads Patel and Kleinman (2003) to conclude that it is important to consider interventions addressing poverty, such as investing in education or providing microcredit, in order to reduce the occurrence of common mental health disorders.

Common mental health disorders are important for my thesis. Measures of anxiety and depression are necessary to identify people with common mental health disorders, and the impact of these on people's everyday activities. However, because measures must be simple, as discussed in Chapter 1, this may lead to simplistic interpretations of the resulting statistics, if the different causal pathways are not sufficiently well recognised. The aim of measurement can only be to identify the presence of anxiety and depression, and not to differentiate between mood states as an illness or as a response to adverse life circumstances. The use of narratives from respondents can elucidate how they understand the cause of any anxiety or depression they may report.

A further look at the factors that generate anxiety and depression is useful to guide the analysis of respondents' explanatory narratives. Patel and colleagues (2001) showed that, in Zimbabwe,depression is seen as being common (even if not clinically diagnosed), and a signal of distress in reaction to a series of individual and community events, such as bereavement, poverty in the household and community, marital crises, and an accumulated effect of ongoing problems. Depression, as marked by a range of chronic physical symptoms, such as heart ache, headache and fatigue, is seen as an indication of illbeing. Thus, depression may be a reaction to an adverse context, where Cummins's (2010) notion of 'homeostatically protected mood' is disrupted. If a person is pushed by adverse circumstances and can no longer maintain a positive level of mood (homeostasis) or satisfaction with their wellbeing, they may experience feelings of anxiety and depression.

Furthermore, the close link between body, mind and spirituality, set out in the notion of healthworlds (Germond & Cochrane 2010) as discussed below, could provide some explanation for the commonly reported somatization (physical expression) of depression and anxiety (Lipowski 1988; Simon, VonKorff, Piccinelli, Fullerton & Ormel 1999). Somatization is defined as tendency to 'experience and communicate somatic distress in response to psychosocial stress and to seek medical help for it, [and it] poses a major medical, social, and economic problem. It is most often associated with depressive and anxiety disorders' (Lipowski 1988: 1358). For example, a person may report generalized pain or fatigue or some other physical symptoms, but there is no diagnosable physical cause for these symptoms. They are physical manifestations of an underlying mental health problem. Somatization is expressed in different ways in different cultures and these different ways have been termed idioms of distress (Scobar, Avier & Gureje 2007; Nichter 2010).

In South Africa, 16.5 % of the population report symptoms of common mental disorders (excluding schizophrenia and bipolar mood disorders) (Williams et al. 2007 cited in Lund et al. 2010) and these represent the third highest contributor to burden of disease in South Africa after HIV/AIDS and other infectious diseases (Bradshaw et al. 2007 cited in Lund et al. 2010). Lund et al (2010) list a range of

factors reported in the literature as being associated with common, mental health disorders: food insecurity, inadequate housing, unemployment, low levels of education, social fragmentation, and violence.

Understanding the social life of a questionnaire requires understanding not only the performance of the questions, but also the life contexts that elicit different responses. I include presence of illness or health problems, availability of social networks and support, financial security, feeling safe, religious beliefs, and, related to all of these, satisfaction with one's life, as a basic list of life context factors. The notion of wellbeing, presented above, provides a useful conceptual framework for looking at these life contexts.

2.3.3 Disability and health

Disability is a component of health and important for health-related wellbeing. The term 'health states' has been used to describe the functioning component of overall health or 'health status' (Task Force on Health Status, 2005). A paper submitted by the Task Force on Health Status (2005) to a joint meeting of European Office of Statistics (EUROSTAT), the UN Economic Commission for Europe (UNECE) and WHO on the Measurement of Health Status, addressed the differences between health states and health status. The paper starts by drawing attention to the need for multiple indicators that must be measured in order to 'provide a full statistical picture of population health' (Task Force on Health Status, 2005: 2), with different indicators for different components. Health state is the functional component, or, more commonly referred to as functional status. Other components include determinants of health conditions; physiological risk factors and risk markers; and diseases, symptoms and injuries that give rise to functional limitations (health states). All these components contribute to quality of life and wellbeing. The model put forward by the Task Force on Health Status identified and associated health status as a whole and, specifically, health states (functional status) as a key component of wellbeing.

2.3.4 Health and wellbeing

The WHO defines health as 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity'.[10] This definition is very broad and shows health to be a key feature of physical, mental and social wellbeing. Since the definition was adopted in 1948, the use of terms 'health-related quality of life' and 'health-related wellbeing'have been used to distinguish between health and wellbeing for analytical reasons, and to denote health as a component of wellbeing. While health is quite central to wellbeing (see review of components above), there are factors that have an impact on wellbeing that are not health or health-related. These include, for example, housing, level of education, and employment status, as described above.

Germond and Cochrane (2010) argue that health and wellbeing are close to being one integrated phenomenon, and show how the reduction of health to only physical aspects of the body has led to a denial of this integration. These authors cite the lack of differentiated terms for 'health' and 'religion' among Sotho speakers in Lesotho as an indicator of this close relationship. They coined the term 'healthworlds' to capture the symbiotic relationship between health and wellbeing. Their criticism of western medicine is that it ruptures this symbiotic relationship by creating a dual system: religion deals with spiritual aspects within the context of formal religious structures (churches, mosques, synagogues, temples), and western medicine deals with bodily (and largely physical) health. The measurement of health-related disability is primarily a concept routed in health rather than religion. However, problems in functioning (or disability) could be expressions of difficulties not only in a health-related sense but also more broadly in a 'healthworlds' sense. This notion of 'healthworlds' provides a possible way of explaining the understanding and interpretation of

[10] Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19 June - 22 July 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, No. 2: 100) and entered into force on 7 April 1948. The definition has not been amended since 1948. Accessed on 5 May 2009 at http://www.who.int/suggestions/faq/en/

disability measures by respondents, that may not fit within a strictly health or disability related framework.

Understanding the complex relationship between disability, health and wellbeing is important to contextualise measures of disability. Descriptions allow for an holistic view of such phenomena with all the inherent levels and complexity, while measurement has to identify components of these that can be measured effectively and accurately. It is important to set out the relationship between these two perspectives – holistic description and measurement. In the above discussion, I set out the framework for the holistic description. In the next section, I discuss the measurement perspective, and specifically measurement of disability.

2.4 Measuring disability

Theconceptual framework for understanding disability and, related to it, health and wellbeing forms the basis of measurement of disability. In this section I present the different approaches to question evaluation to determine the performance of these measures. A good measure is valid, transparent and well understood, as intended by the question designers.

Approaches to researching disability must find ways to accurately measure complexity. The current status of disability measuresis in the early stages of developing measures for all the required components. These measures have focused on the most basic and easily measured components, with the understanding that we still need to develop measures for the remaining components of disability.[11]These measures must be valid, provide comparable measures across different populations, and allow the complex relationships between different components to be reflected. The traditional approach of asking about being 'deaf, blind, crippled or mentally retarded',can be

[11] The work of groups such as the Washington Group on disability Statistics are undertaking work, as their ongoing agenda, on developing measures for all the components, including participation and environmental factors.

seen as simple measures, but the difference is in the validity and transparency of the measures, as shown by Schneider (2009) and to be investigated further in this thesis. These traditional disability measures are limited and lacking in comparability,as they do not acknowledge the complexity of disability (as discussed above). They have generated a very wide range of statistical estimates that bear little resemblance to one another or defy clear interpretation (UNSD n.d.; Schneider 2009). As mentioned in Chapter 1, the growing body of work on question evaluation for measuring disability is primarily located within high income or developed countries, with Canada, Australia and the USA being good examples. Little work has been done in low/middle income or developing countries. I discuss this work and the way in which my thesis adds to it in section 2.4.2 below.

In this thesis, I consider measurement from two perspectives - a public health perspective (Why does the field of public health need disability statistics?) and a human rights and equalisation of opportunities perspective (What role do disability statistics have in equalisation of opportunities for people with disabilities?). At the start of this section, an historical review of disability statistics and of the current juncture shows how the same measures can be used for different purposes, for example, by both public health and the disability movement. This is followed by a description of the current approaches to disability measurements, introducing the measures that are the focus of this thesis. These measures are the Washington Group on Disability Statistics Short Set (WG Short Set) and Extended Set (WG Extended Set) (Washington Group 2008; UNESCAP 2010), and the WHO's set of questions used in the Global Study on Ageing (SAGE) (Sankoh 2010; Kowal et al. 2010). The third section examines the methodological aspects of measuring disability and how this is addressed in this thesis.

The performance of these measures is analyzed from three different angles: a) the effect of the wording of a question ('disability' vs 'difficulty'); b) respondents' interpretation of the whole question (cognitive testing); and, c) the association of life context factorswith different profiles of functioning related to severity and type of difficulties. These, together, provide the basis of

determining the validity of the disability measures and the potential sources of respondent error in disability statistics.

2.4.1 Who needs disability statistics?

The public health and disability sectors are (or should be) two important users of disability statistics.[12] The number of people with disabilities in any population remains an elusive estimate. However, even with limited data, it is clear that people with disabilities are over-represented among poor people (Elwan1999; Burchardt2003; Thomas 2005), are socially excluded (Dickson 2003; Schneider et al. 1999), and remain disadvantaged because of their impairments. Accurate data that are also nuanced, beyond a simple categorization into 'disabled' or 'non-disabled', will assist in galvanising relevant resources, monitoring and evaluating interventions aimed at equalization of opportunities, and mainstreaming disability in data collection platforms. Currently, there is a lack of such data, and, at times claims are made without substantiation. The oft (and mostly uncritically) quoted 10% world prevalence of disability advocated by WHO in the early 1980s (Helander 1993) is a good example of such an unsubstantiated estimate. The recently published estimate of 15.6% of the adult population globally 'experiencing significant functioning in their everyday lives' (WHO 2011: 27) is a good example of a more substantiated estimate based on data from the World Health Survey (WHS). The questions used in the WHS are the same as those used in the SAGE, and evaluated in my thesis. Accurate data are required for managing disability, and complement other interventions, such as awareness raising to change attitudes; focus interventions, such as addressing environmental barriers; and adopting a human rights approach to disability, or, in other words, moving away from a narrow medical, welfare or charity approach to disability that focuses only on the individual.

[12] While I am only including two main constituencies, I am cognizant of the importance of disability statistics for almost any constituency, including national education, health, labour, housing, and social development departments. However, their need can be subsumed to some extent to that of the disability sector, as they would also be looking at monitoring redress of inequalities for people with disabilities.

The field of public health needs measures on disability to monitor population health more effectively. The use of functional status measures allows for a better predictor of health service usage and health outcomes (WHO2001). Diagnosis is insufficient information to accurately predict, for example, the number of days required as an inpatient or the outcome of an intervention (Bickenbach et al. 1999). Public health interventions and advances in clinical medicine have led to a health transition, with increased chronic illness and better survival rates. As a result, it becomes important to consider not only mortality and morbidity, but also the consequences of living with a health condition for a person's everyday life. Hypothetically, two people with similar stages of AIDS illness and on antiretroviral therapy (ART) may show different functional outcomes. One person may benefit greatly and improve his or her ability to walk, take care of themselves and communicate, while the other may not experience such significant changes in their functional status. These functional differences could provide explanations for potential differences in, for example, adherence to the ART schedule. However, in order for such links to be made, we need accurate measures of functioning. Similarly, a woman living in a rural area who has to fetch her water and firewood, and who struggles because of severe asthma, will benefit greatly from asthma treatment. The cost effectiveness of providing such asthma treatment is best measured by information that considers clinical aspects, such as peak flow measures, together with the functional impact on individual livelihoods.

Accurate data on functional status will not only complement clinically based cost effectiveness measures for the health system, but also provide cost effectiveness measures for individuals and their ability to sustain a livelihood. This latter consideration has repercussions in providing other services, such as social assistance, in the form of cash transfers by government departments other than health. In this way, a comprehensive social protection system is slowly constructed.

Given that public health professionals need good functional status information, it is imperative, as the IEA European Questionnaire Group (no date: 9) conclude from their review of existing

questionnaires, that 'epidemiologists need to take the development of research instruments and the validity of questionnaire data more seriously'. These authors argue that using better validated and standardised questionnaires is necessary in the field of epidemiology and public health for the following reasons: a) improved data quality through identifying and correcting errors in the questions; b) enhancing comparability to allow for meta-analyses; c) reduce duplicated effort of developing new questionnaires for each data collection exercise; and d) improved credibility of the field, and quality and usefulness of the information obtained.

Thomas (2006: 1) summarizes the important uses of population level disability statistics as 'monitoring the general health of the population, formulating and monitoring disability benefit policies, assessing needs for care in the community and the role of paid and unpaid carers, assessing the impact of disability on employment and employability, and, assessing the impact of disability on quality of life'. These uses all serve different sectors of government and civil society and at different levels of service provision, and international and national policies through to local service delivery. The benefits of using a valid and understood measure of disability are that the same data and measurement tools can be applied at all levels of use.

2.4.2 A brief history of disability measurement

Historically, the measures used to collect disability statistics have mirrored the contemporaneous views on and understanding of disability. Prior to the start of the exponential growth of awareness and interest in disability in the 1960s and 1970s (which continues well into the second decade of the 21st century), the terms used for disability were limited to extremes such as 'deaf (usually together with dumb), blind, mentally retarded, and crippled' giving rise to questions such as 'Is anyone in this family deaf, blind, crippled or mentally retarded?' (see UN Disability Statistics database (DISTAT) for 1980s and early 1990s). These measures yielded very low estimates of prevalence, often below one percent, and contributed to the continued exclusion of disabled people from the mainstream of society. The small numbers allowed governments to relegate 'the disabled' to institutions and lives

of exclusion from mainstream society (Dr IzabelMaior, personal communications, 2008[13]). Fear and intolerance of 'deviance' were managed through provision of charity and institutions. No consideration was given to the wellbeing of people with disabilities beyond their basic physical comforts, and, sometimes, not even to these basic needs. Wellbeing and social justice were hardly a consideration.

Further examples are the questions used in censuses and surveys, as reported by countries in the UN Statistics Division's Disability Statistics database (DISTAT), from mid-1990s to early 2000 (UNSD, no date). The questions listed in DISTAT are good examples of the traditional approach to disability measurement, which is to count impairments and only severe ones. In addition, these measures use a dichotomous variable – one is either disabled or not, and the response options limited to 'yes/no'.

A review of DISTAT – the UN's disability statistics database – shows that between 1995 and 2004[14], 40 out of 81 countries, the majority low or middle-income countries, usedthe terms 'disability' and/or 'disabled' in their census or survey questions. High income countries, such as the USA, Canada, and UK, did not use these terms or used them with other phrases, such as 'difficulties' or 'long term illness,' which may have neutralised the loaded use of 'disability', as evidenced by the high prevalence estimates reported in DISTAT.

These measures reflect the medical model, discussed above. If medical cures or rehabilitation did not 'deal' with the disability, disabled people were relegated to institutions (Schneidert et al. 2003) and 'out of sight', the title of a book on experiences of disabled people in the United Kingdom (Humphries & Gordon 1992).

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[13]Dr Izabel Maior. Rehabilitation Physician, Brazil. Personal communication, World Bank workshop on disability statistics, April 2008, Bangkok, Thailand.

[14] See http://unstats.un.org/unsd/demographic/sconcerns/disability/disabmethods.aspx,

The measurement of disability has undergone significant changes over the last 30 years. Subsequent to the International Year of Disabled Persons 1981 and the development of the Standard Rules for the Equalization of Opportunities for Persons with Disabilities (UN 2003-04), measurement of disability started gaining ground, with an increasing number of countries collecting disability data on censuses and surveys (Swanson, Carrothers&Mulhorn 2003; Schneider et al. 1999). These surveys asked a wide range of questions about difficulties people had in doing various activities. The response scales went beyond a simple binary yes/no, yielding higher prevalence estimates.

The growing interest in developing more standard measurement tools led to the United Nations Statistical Division hosting an international workshop in New York in June 2001, to look specifically at disability measurement and statistics.[15] An outcome of the workshop was the establishment of the Washington Group on Disability Statistics (WG), a city group reporting to the UN Statistical Division, but run independently of the UN structures.[16]

The objectives of the WG were, and continue to be,

- To guide the development of a small set(s) of general disability measures, suitable for use in censuses, sample based national surveys, or other statistical formats, which will provide basic necessary information on disability throughout the world.
- To recommend one or more extended sets of survey items to measure disability or principles for their design, to be used as components of population surveys or as supplements to specialty surveys. These extended sets of survey items will be related to the general measures.

[15] I attended that workshop and the subsequent WG meetings, and continue to do so into 2012.

[16] See http://unstats.un.org/unsd/methods/citygroup/index.htm - accessed 13 June 2009 – for more information on the UNSD's various city groups.

- Measures identified in objectives 1 and 2 will be culturally comparable to the extent possible. The ICF model, a useful framework to assist in the development of these measures, will be utilized in developing the measures.
- To address the methodological issues associated with the measurement of disability considered most pressing by the City Group participants.[17]

The first meeting of the WG was held in Washington DC, USA (hence the name of the group) in February 2002. It was attended by delegates from 32 countries, comprising some 64 participants, including representatives from disability organisations. This is by far the largest city group to have been set up by the UNSD (J Madans, personal communication[18]), demonstrating the interest given to disability internationally. The WG hosted its eleventh meeting in November 2011 and aims to continue for another few years.

The main outcome of the work of the WGby late 2010 was a Short Set of six questions for use in censuses, where typically space on the questionnaire is at a premium. This Short Set was tested in a number of countries, both developed and developing, and it appears to produce reasonably comparable measures of disability (Miller et al. 2010; UNESCAP 2010) .As of 2010, many countries are starting to use this WG Short Set on their censuses, generating more data for use in international comparison. Statistics South Africa has, since 2009, used the Washington Group Short Set in its annual General Household Surveys, and included them in the Census of 2011. The development and testing of the WG Short Set questions has shown that the questions tap into the construct of disability and functioning (Miller et al. 2010; UNESCAP 2010).

[17]WG Website, accessed 13 June at http://www.cdc.gov/nchs/about/otheract/citygroup/objectives.htm

[18] Dr Jennifer Madans, Associate Director For Science and chair of the Washington Group on Disability Statistics

The WG Short and Extended Sets aim to identify the population at risk for experiencing the disadvantages typical of disability. The set comprises a single question each for six domains of functioning – seeing, hearing, mobility, cognition, self-care and communication. While this Short Set seems to provide reasonably good measures (or certainly better ones) of population functioning, it is limited in that only one question is asked and only of a limited set of domains of functioning. The population thought to be most excluded from these measures (i.e. not counted in) are people with psychiatric and emotional disabilities, especially the common mental health disorders discussed earlier in this chapter. [19] The aim of the Short Set was to create a demographic variable that can be used in further analysis, as measures of sex and age are used. Disability is not only about difficulties seeing, hearing, walking, remembering and concentrating, washing and dressing, or communicating, but about the effect of these difficulties when they interact with a person's environment to create disadvantage, such as loss of employment, limited education, and social exclusion, as I discussed earlier.

The WG's Extended Set of questions is currently being developed to complement the Short Set, in order to provide a more comprehensive count of people at risk of experiencing disability related disadvantage. This set was evaluated through cognitive interviews and field testing in six countries in the Asia Pacific region (UNESCAP 2010). In addition to these six countries, a further five countries, including South Africa, undertook cognitive testing interviews. Five of the interviews analyzed in Chapter 5 were included in this international study. Work on the Extended Set is continuing internationally.

Thus, a full description of disability in a population comprises measures using the WG Short Set or Extended Set, together with questions on complex activities such as working, attending school, social interactions, and civic engagement. The level of participation in these life areas is analyzed in

[19] See WG meeting documentation at http://cdc.gov/nchs/washington_group.htm

relation to the degree and type of difficulty people report. The results of this analysis are the disabilityrelated disadvantage people experience.

Parallel to the WG initiative, other initiatives also looked at developing measures of disability. A number of countries have been testing and evaluating their disability measures used in disability surveys. This work has been predominantly in high income or developed countries, including USA, Canada and Australia as good examples, where much effort has gone into developing good measures of disability or at least to understand how these measures perform.

In addition, there has been more internationally focused work, such as the WHO Disability Assessment Schedule (WHO DAS II) (Rehm,Üstün, Saxena, Nelson, Chatterji, Ivis& Adlaf 1999; Luciano et al. 2010), the Budapest Initiative (a joint initiative between EUROSTAT, WHO, and UNECE) (Task Force on Health Status2005a,b), and WHO's multi country studies – surveys on health and wellbeing, including the WHS 2002/2003 and the SAGE (Murray and Evans 2003; Sankoh 2010; Kowal et al. 2010).

The Australian efforts (Black 2001) have been largely related to the differences between response rates in censuses and surveys, and on the use of scaled response options compared to a dichotomous yes/no. Their findings showed that it is difficult to get a good match between estimates from censuses and surveys, but that using a scaled response provided less false negatives in the census question schedule and hence provided a better match with responses from survey data (for similar samples); they attribute this to the use of scaled response options rather than a dichotomous response option of yes/no.

They concluded that more cognitive testing was required of specific questions which yielded non-matching estimates across different surveys and population subgroups.

The questions they used often included both the words ‘disability’ and ‘difficulty’ such as in the example provided below which was used as part of the testing of disability measures in 1998 from the 2001 census (Black 2001):

18. How much difficulty does the person have in:
    - doing everyday activities such as eating, showering or dressing?
    - hearing?
    - learning, understanding or remembering things?
    - reading or seeing even with glasses?
    - walking, kneeling or climbing stairs?
    - living independently?
    - doing any other things people of the same age usually do (for example working, studying, etc.)

    The response options were:
    None
    A little
    A lot

19. What causes the difficulty shown in Q18 for the person?
    - Short-term health condition (lasting less than six months)
    - Long-term health condition
    - Disability
    - Age
    - Difficulty with English language
    - Other cause - please specify

The word ‘disability’, however, is not highlighted or given prominence in these questions as it is in the more direct questions asking ‘Are you disabled?’ or ‘do you have a serious disability.....’, nor do they use terms such as ‘deaf, blind, crippled or mentally retarded’.

In the USA work has been carried out on various survey questions at the National Center for Health Statistics Question Evaluation laboratory (Miller 2003; Miller & Willson 2009). While this work is most closely aligned with my thesis, most specifically in relation to the cognitive testing interviews analyzed in Chapter 5, it does not directly address the difference between ‘difficulty’ and ‘disability’. The work in the USA has focused more on whole question interpretation and how these feed into revisions of questions prior to a survey being run.

The work undertaken by Statistics Canada (2002) focuses on developing screening questions that best identify the population with difficulties in a census that can then be followed up by a post-censal survey. Through careful testing of the questions, the filter questions used in the 2001 Canadian survey were much more inclusive than those used in the 1991 survey. This resulted in less false negatives in 2001, when comparing the Census to the post-censal survey data. The 2001 screening questions provided better measures to identify non-physical disabilities, including learning disabilities, developmental disabilities and emotional disabilities. These types of disabilities were lumped into the 'other' category in the 1991 screening questions, thus giving more weight to the physical and sensory disabilities. In addition, the severity was rated according to a three-point scale in 1991 (mild, moderate, severe), and a four-point scale in 2001 (mild moderate, severe and very severe) (Statistics Canada 2002). They found that the four point scale improved the severity weighting across the different types of disabilities. This Canadian work provides useful information on the use of census followed by a post-censal survey for measuring disability, but did not evaluate the difference between 'disability' and 'difficulty' specifically.

High income countries have been in the forefront of developing awareness, enacting anti-discrimination policies related to disability (e.g. as the Americans with Disabilties Act of 1990 in the USA - see www.disabled-world.com/disability/ada/), and increasing services to people with disabilities. This has been underpinned by the need to change the approach to measuring disability – making the importance of collecting disability statistics essential in order to monitor these policies.

Furthermore, these countries have developed new measures of disability based on the ICF and its predecessor, the ICIDH, that shifted measures of disability away from the categorical measures of 'deaf, blind, crippled or mentally retarded'. However, much of this shift occurred prior to the development of a strong question evaluation methodology for surveys, such as reflected in the Cognitive Assessment of Survey Methodology (CASM), described earlier in this thesis. This has resulted in limited or no documentation of the shift from the more categorical measures to the more

nuanced current measures. Thus we do not have published or accessible studies on the specific effect of asking about 'difficulty' vs 'disability'. My thesis contributes by documenting this difference, and for a middle/low income context.

The reason why it is important to document this difference is the continued use of the categorical and strongly 'disability' focused measures in many censuses and surveys, predominantly in low/middle income or developing countries, as reflected in the DISTAT database of survey and census questions (UNSD n.d).

The focus of the international initiatives has been different to that of the country specific work. While the country specific work focused on question evaluation using qualitative methods, the international work has used more quantitative methods for the validation of survey questions. These latter efforts have focused on population health (and not disability specifically) and on finding a parsimonious set of questions that explains the majority of the variation of health states or functional status (Task Force on Health Status 2005a, b). These sets of questions are used for summary measures of health and, for example, in the assessment of health system performance as set out in the 2002 World Health Report (World Health Organization 2000) and the Global Burden of Disease calculations (Murray & Evans 2003).

The WHS aimed to develop a means of providing low-cost, valid, reliable and comparable information (Ustün, Chatterji, Mechbal, Murray & WHS Collaborating Centres 2003a), and SAGE, as a follow-on from the WHS, is, according to the website (circa 2006):

> a longitudinal survey programme to compile comprehensive longitudinal information on the health and well-being of adult populations and the ageing process. The core SAGE collects data on respondents aged 18+ years, with an emphasis on populations aged 50+ years, from nationally representative samples in six countries (China, Ghana, India, Mexico, Russian Federation and South Africa). (World Health Organization n.d.)

The questions used in the WHS and SAGE surveys are based on the WHO's Disability Assessment Schedule II (WHO-DAS II). The concepts used in the WHO-DAS II were tested using a mix of qualitative and quantitative methods, and across a number of settings in the late 1990s (Ustün, Chatterji, Bickenbach, Trotter &Saxena 2001). The resulting book by these authors entitled *Disability and Culture: Universalism and Diversity* (Ustün et al. 2001) presents the results of this research, which aimed to ensure that the revisions of the ICIDH to the ICFand the WHO-DAS II were cross-culturally applicable. The methods (p.16) aimed to determine the following:

- *Functional equivalence*: can one define similar domains of activities in different societies and cultures that serve the same function in different cultures?
- *Conceptual equivalence*: is there an equal understanding of the meaning of disability concepts across cultures?
- *Metric equivalence*: do the measured constructs exhibit essentially the same measurement characteristics in different cultures?

The methods used included (p.18-30)

1. A detailed description of the disablement process in each culture or cultural setting;
2. Linguistic analysis of each assessment item (domain, sub-domain and specific item), within the ICIDH-2, and used to 'determine the semantic and conceptual equivalence of terms' (p30) across the different languages of the study;
3. Concept mapping for each assessment item to see how people 'cognitively map out the territory of a concept' (p29);
4. Key informant interviews that focused on local understanding of disability and general prevalence of various conditions;
5. Pile sorting of assessment items to see how people group concepts and compare these across settings; and

6. Focus groups 'to explore collective views on particular cultural conditions' (p27).

These methods allow for a detailed and rich exploration of the classification structure and content, and cross country comparability for the concepts embedded. The results show the universal applicability of the ICF. However, the classification is not an assessment tool and, despite the research undertaken by WHO to identify items for use on health status measurement tools (Ustün et al 2001), the study did not test the performance of the actual written questions in the WHO-DAS II, unlike the country-specific work. Thus, while the domains of the ICF are clearly universal, formulating questions to measure these domains is a different exercise. While question evaluation has not been undertaken for the WHO-DAS II, it has been used on a series of international survey platforms, starting with the Multi-country Surveys Study in 2000 and 2001 (Ustün, Chatterji, Villanueva, Bendib, Çelik, Sadana, Valentine et al. 2003b), revised for the World Health Survey run in 70 countries (Ustün et al. 2003b), and the Global Study on Ageing (SAGE), (Sankoh 2010; Kowal et al. 2010). In each of these survey platforms, the questions have been used to assess health states as a component of health status (Task Force on Health Status 2005a). The SAGE questions were used specifically in one of the sites included my study – the Agincourt Health and Population Unit site in Mpumalanga, South Africa.

The two uses of functional status data – on equalisation of opportunities (WG Short and Extended Sets), and on population health or consequences of a health condition (WHO-DAS II) – overlap. Both use the ICF as an overall framework for understanding disability,ask questions on 'difficulties' people have, and use a scale of response options (four for the WG questions and five for the WHO-DAS II and SAGE). Thus, the disability model and measurement principles underpinning them are the same. The aim is to measure the level of functioning of respondents. This is in contrast to respondents' level of satisfaction with their level of functioning, which also uses a subjective measure.

In summary, the contribution of my thesis is to continue the work undertaken in high income countries and internationally by documenting what seemed to have been taken for granted (quite rightly) a good two to three decades ago on the importance of wording. In addition I focus on a middle/low income context, and undertake rigorous question evaluation to complement the concept mapping work described above for WHO-DAS II. Furthermore, in my thesis I juxtapose the responses given by respondents to the questions with their explanations of disability as a phenomenon, a feature not noted in the literature I could find. Lastly, given that my thesis used data collected for evaluating the disability schedule as part of StatsSA's content research for the South African census of 2011, it was imperative that I compare the census 2001 questions and 2011 proposed questions as part of the methodology.

In this way my thesis goes back in time (by focusing on disability vs difficulty) as a basis to go forward in building our understanding of disability measures and how people understand disability.

2.4.3 Methodological aspects of questionnaire development and testing

In this section I discussself-report social surveys and potential sources of errors in the data collected. I then describe current approaches to researching these errors and their potential impact on data and statistics. I briefly review the concept of validity testing and its relationship to this thesis.

In 1996, Sudman, Bradburn and Schwarz (cited in Gonzenbach 1997: 88) described social surveys as being

> a special type of conversation with characteristics that set it apart from many other conversations, but it is a conversation nonetheless and needs to be understood as a conversation …Thus, understanding the rules that govern conversation and social encounters in general should help us understand how survey questions are being understood and answered.

In his review of Sudmanet al.'s book on *Thinking about Answers: The Application of Cognitive processes to Survey Methodology*, Gonzenbach (1997: 88) highlights how understanding what surveys are measuring requires an understanding of how people understand and process speech, as well as 'how people understand the world around them and how they communicate with one another'.

Willis (2005) describes the increased use of self-report surveys in a wide range of social science disciplines since the mid twentieth century, concurrent with the 'ascendence of the subjective realm' (Converse, 1987, cited in Willis 2005: 13), which Willis contrasts with an 'earlier more purely objective and behaviorist approach' (p.13). Self-report surveys require responses about oneself, to questions about attitudes, views, individual characteristics, for example difficulties in doing various activities, and other demographic information. Wolfe (2002: 865), when describing the use of these measures in the field of rheumatology, suggests that there is room for improvement of self-report questionnaires: 'Although widely used, questionnaires [on functioning] and their interpretation represent a pleasant mixture of the familiar, the impenetrable, and the incomprehensible'.The increased use of self-report surveys drew attention to the numerous possible errors in the data collected, and led to research to elucidate this impenetrable and incomprehensible nature of interpretations by respondents.

The field of cognitive psychology has been in the forefront of research on questionnaire design and understanding the processes that people apply in answering questions on surveys. The advances of cognitive psychology allowed survey methodologists to theorize why and how people respond to survey questionnaires. The marriage of survey methodology (including questionnaire design) and cognitive psychology shifted the focus from effects of survey errors to causes of survey errors (Tourangeau 2003). If the focus of survey methodology is to find ways to reduce errors, then it becomes important to understand how respondents act as a significant source of error. In the mid

1980s, advances in cognitive psychology were applied to survey methodology with the aim of reducing errors arising from respondents (Tourangeau 2003).

a) Sources of error in self-report survey data

Willis (2005: 14) describes three major sources of error in survey data. The first are errors of non-observation, which answer the question: 'Are we surveying the right people?' These errors include coverage, sampling and non-response errors. The second sources of errors are those of observation, which answer the question: 'Are we getting the right answers?'. These errors include interviewer and response error. The latter is the focus of my thesis and comprise the characteristics of questions and respondent processing of those questions. The third sources of errors are post-observation errors, which answer the question: 'Are we doing the right thing with the data?' these errors include data processing and interpretation errors.

While the first and third sources of error are, respectively, within the domains of sampling and statistical expertise, the second source is within the domain of questionnaire design. Willis (2005: 15) concludes that '[r]esponse error is a major impediment to survey data quality, and the design of questionnaires that are sufficiently free of such error is a complex process that requires the use of systematic principles of both question design and empirical evaluation'. My aim in writing this thesis is to contribute to the body of empirical evaluation.

Indications that response errors exist come from:a) checkingself-report responses against existing objective records, such as reported age against a birth certificate; b) repeat interviews and comparison of responses across the two interviews; and, c) research on the effect of wording changes on responses (Willis 2005). The earlier work on observation errors focused on the role of interviewer aspects on the survey process. Schwarz (2007) cites the meta-analysesdone by Sudman and Bradburn from the early 1970s as evidence suggesting that the nature of the task (i.e. responding to survey questions) had a much larger effect on responses than the characteristics of

either the interviewer or respondent. Bradburn (1978: 35)directly addressed the need to look at the characteristics of the task in his paper on respondent burden. He commentedthen that, while considerations of potential respondent burden was 'part of everyday practice' in survey work, more effort was required to develop a more conscious research agenda to understand this potential burden. He listed the potential sources of respondent burden as being the length of the questionnaire, respondent effort required in answering questions on more familiar versus less familiar topics, respondent stress generated by discomfort during the interview process, and the frequency of being interviewed in, for example, longitudinal surveys. While these characteristics remain important to consider, Bradburn's plea was heard and important research on task characteristics has been undertaken in the 1970s, culminating, amongst others, in the current field of Cognitive Assessment for Survey Methodology movement (Willis 2005; Tourangeau 2003).

b) Validity and reliability

Validity and reliability are basic to assessing test and questionnaire performance(Cook & Beckman 2006; Latcheva 2009; Sartori&Pasini 2007). Sartori and Pasini (2007:359) comment that defining and testing validityis 'both an old question and a never-ending story'. It is a necessary step in constructing and using tests, especially as psychological testing (the topic of their paper) is context-dependent.While psychological testing is not the topic of my thesis, the notion of validating a test is similar to that of question evaluation or validating the performance of survey questions.

Cook and Beckman (2006) define validity as the trust one has in the results of a test within the testing context. These authors caution that results of any test, (orsurvey questionnaires), are only meaningful within the boundaries of construct they are assessing. Thus, they say, the first step in evaluating validity is to provide a clear definition of the construct being measured. Messick (1995: 741) underscores the role of validity as being about giving meaning to test scores within a context – a central theme of my thesis – whenhe says that:

> [v]alidity is not a property of the test or assessment assuch, but rather of the meaning of the test scores. Thesescores are a function not only of the items or stimulusconditions, but also of the persons responding as well asthe context of the assessment. In particular, what needsto be valid is the meaning or interpretation of the score;as well as any implications for action that this meaningentails.

Cook and Beckman (2006) list content, criterion, and construct validity as different types of validity that have historically been includedas components of validity testing. These, they argue, have now been subsumed under the single rubric of construct validity, with the different types being understood as sources of evidence of construct validity. They describe five such sources of evidence: content, response process, internal structure, relations to other variables, and consequences. Content evidence considers whether the questions reflect the construct under measurement in all its dimensions–disability for my purposes. The response process evidence comprises the way respondents think about and respond to the questions in order to understand the underlying interpretations and understanding that the respondent or observer applies when responding or observing. This evidence is obtained through asking respondents or observers to 'think aloud' (as stated by Cook & Beckman, 2006) – a technique used in survey question evaluation. Evidence on the internal structure is obtained from: reliability coefficients and factor analysis; relations to other variables, from correlation with scores from other instruments; and consequences from unintended bias as noted between different groups of respondents or observers (Cook & Beckman 2006).

Cook & Beckman (2006: 166.e12) caution on the use of face validity as, they argue, this notion 'bases judgement on the appearance of the instrument' rather than a 'systematic and documented approach to ensure that the instrument assesses the desired construct', which they define as content evidence. They suggest that the notion of face validity should not be used. Sartori and Pasini (2007: 363), while describing face validity as a useful component of validity, caution that 'even if a test has face validity, it does not mean it will be *valid* in the technical sense of the word'. Evidence of

face validity would be if respondents feel that the questions asked are relevant to their lives and to their functioning. The Task Force on Health Status (2005b) refers to face validity as a feature of how measures of health are perceived by respondents. The Task Force stipulates face validity as one of the criteria to be applied in the selection of health domains for measures of health state and functioning, and, for their purposes, face validity means 'that the domains of health selected will be immediatelyseen as plausible and reasonable by ordinary individuals…. A fundamental reason for this criterion is that the health status measures need tobe credible with a broad public' (2005: 2).

In contrast to validity, the measure of reliability is relatively simple and is done using statistical tests, such as alpha coefficients or Kappa scores (Sartori&Pasini 2007). Reliability refers to 'the reproducibility or consistency of scores from one assessment to another' for the same rater over time, for two raters for the same respondent, and for different respondents, and is a 'necessary, but not sufficient, component of validity' (Cook &Beckman 2006: 166.e12). I do not address reliability in my thesis.

In conclusion, this short discussion on validity highlights its importance in developing tests and, for my purpose, survey questionnaires. In other words, if the measures are valid, we can be confident in our interpretation of the data generated. In this thesis, I focus on providing evidence on content, response process and face validityas part of validating disability measures. None of these aspects of validity are assessed statistically.

Establishing validityallows for the necessary revisions to be made prior to finalising and applyingthe questionnaire in a survey. Thus, my concern in this thesis is to assess the performance of disability measures as a contribution to establishing their validity. Once the measures are applied on a large population based sample, statistical measures of validity and reliability can be applied.

2.4.4 Factors generating response errors

In exploring the performance of disability measures in the context of response errors, three levels of investigation and analysis are important to consider: a) wording used in the question; b) the whole question, its context within the questionnaire, and response processing; and c) the life context factors associated with various response profiles.[20]

a) Question wording

A study on attitudes towards 'allowing' or 'forbidding' speeches against democracy (Rugg, 1941, cited in Schwarz 2007) showed that Americans were more likely to respond 'no' when asked 'Are you in favour of forbidding freedom of speech?' than 'yes' when asked 'Are you in favour of allowing freedom of speech?'. They rejected 'forbidding' more than they endorsed 'allowing'. Replication of similar experiments suggest that the differences in responses are driven by 'indifferent respondents' who answer 'no' to both options as they 'prefer a 'do-not-do-anything-about-it' response' (Schwarz 2007:281).

In the field of disability, wording effects have also been documented. Meltzer (2003) reported the effect of asking about 'having' versus 'suffering' a condition. The number of people who report 'having a condition' (a neutral term) is higher compared to those who report 'suffering from a condition' (a loaded term). The implications are that having a condition is not necessarily seen as suffering. In this thesis, I consider the effect of asking about 'difficulty' versus 'disability'. I argue that difficulty is a more neutral term than disability, and the reason why developing countries tend to ask survey questions that ask about difficulties rather than disability (Mbogoni & Me 2002).

While wording changes can cause significant effects on data obtained, testing of different wording does not necessarily provide clarity on which wording is the correct one. We should understand these differences and then decide which formulation yields a better result (Willis 2005).

[20] Profiles are in relation to individual responses to the whole set of questions.

b) The question and its context within the survey

Much work has gone into understanding the effects of the question, its response option and its context within the survey. The studies have focused on aspects such as using a 0 – 10 versus -5 to +5 response scale, complex versus simple questions, placing a question at the start or end of a survey, and asking the same question in a topic-specific versus general survey. Schwarz (2007: 280) lists a number of characteristics that have been known to affect people's responses, predominantly in the field of attitude measures, and states that 'contextual influences on attitude judgements are not an artefact but part and parcel of the phenomenon of interest'. Some of the elements raised by Schwarz as being important include the visual format of the questionnaire, the context of the survey, standardisation of the wording and the response options provided.

The visual format of the questionnaire, including the letterheads that indicate who is collecting the data, and the survey title, provide a context for the respondent. For example, if a survey is introduced as a general household survey asking about a range of topics, the focus of the respondent will be different than if it is introduced as a health or disability survey, which has a narrower focus. Similarly the same questions asked in a different survey may elicit different responses. For example, a question on workplace behaviourwill receive different responses depending on whether it is asked as part of a 'sexual harassment survey' or a 'work atmosphere survey' (Schwarz 2007).

The wording of questions in surveys can either be kept strictly standardised, and if a respondent requests for clarification or a repetition of the question, the wording and question structure is maintained, or there can be some flexibility, where the question is clarified using other words or even, from my experience of observing numerous administrations of survey interviews in field, changing the question wording. The former retains the standard nature of the survey with the risk of losing the respondent's interest and attention, whereas the second maintains a conversational approach to the interview with an aim to maintain the respondent's attention and interest. For

factual questions, that ask for example, about the number of rooms in a house, a flexible approach is more applicable than for questions that ask, for example, about opinions and attitudes.

The response options and scales provided also influence the responses. When a respondent is asked about the frequency of occurrence of a behaviour, the respondent uses the response options as a way to interpret the intent of the question (Schwartz 2007). For example,if one of the response options is 'today' when asking feeling angry, the respondent could extrapolate that the question is asking also about trivial everyday instances of anger. Similarly, if the response options include 'weekly' as the most frequent occurrence, the extrapolation made is about more serious incidents of anger and not trivial, daily ones.

Thus, the context of the question and its response options are important determinants of responses given inself-report surveys. The notion of context, in this instance, is referring strictly to that of the questionnaire and survey. There is a broader notion of context that potentially can affect people's responses to questions. This is what I have called the life context.

c) Life context

Context comprises the interface between one's life experiences and current living context on the one hand, and, on the other hand,one's understanding of the role played by these in determining one's health and overall wellbeing.

There are a number of factors to consider, but it is not clear how these interact or exactly what influence they have on people's responses. Cultural beliefs and practices related to health and disability, socio-economic status, social networks and support are all potential factors that can influence these responses.

i. Health beliefs and practices:

The notion of health, religion and wellbeing existing in a symbiotic relationship, where mind and body, person and society, lifeworlds (as pertains to individuals' sense of themselves) and systems(as systems within which individuals live) are all considered important (Germond & Cochrane 2010), is strongly evident in societies that have maintained active links with their historical culture and ways of thinking. Lifeworlds, as described by Habermas (1987, cited in Germond & Cochrane 2010) are the individual's experiences of the world in which he or she lives. Thus, the Sotho people in Lesotho do not differentiate between health and religion, and struggle with a formal health system that ignores or sidelineslifeworld concerns and only focuses on physical health (Germond&Cochrane 2010). In Northern Malawi, the Tumbuka people see some illnesses as being ancestor-related and, hence, not amenable to treatment through the formal or traditional health system (Munthali 2006). The 'treatment' is through talking to the ancestors to appease them. The goal of ancestors is to generate peace and wellbeing.These beliefs and practices are central to respondents' understanding of their health and wellbeing, which, in turn, may affect the way they respond to questions on functioning. If they do not separate health and religion or spirituality, their responses on questions on functioning should reflect difficulties whether the cause of the problem is a health or spiritual one. They may not limit their reported functional difficulties to those strictly health related.

ii. Socio-economic status and social networks:

Common mental health disorders (excluding severe illnesses such as bipolar disorders and schizophrenia) are related to one's social capital (de Silva, Huttly, Harphan&Kenward 2007) and the level of trust, safety and material security in people's lives. These relationships are specifically evident in low resource contexts (Lund et al. 2010; Patel 2001). Depression in Zimbabwe was found to be closely linked to a cycle of depression, poverty and disability (Patel 2001). Germond& Cochrane (2010: 319) describe how healthworlds and the related 'religious discourses, rituals and prescriptions' have, as a goal, comprehensive wellbeing. They construe these acts as 'usually

including both individual life and the relational context of the individual in family, community, society and environment'.

The socio-economic context of people's lives has an important impact on their wellbeing, as described above, and, particularly for my thesis, with health (Montgomery 2009;Khan, Hotchkiss, Berrutti & Hutchinson 2006). In developing countries, there has been a notable health and demographic transition with an increased prevalence of infectious and non-communicable diseases (Kahn et al. 2007; Tollman, Kahn, Sartorius, Collinson, Clark & Garenne 2008; Mayosi, Flisher, Lalloo, Sitas, Tollman & Bradshaw2009; WHO 2011). This increase is notable in both urban and rural areas and particularly affecting poorer communities. This situation requires increased efforts of surveillance and health provision that is accessible and affordable (Mayosi et al. 2009). The costs associated with seeking heath care are often not so much the actual fees for services but other costs such as transport to access the health care services (Goudge, Gilson, Russell, Gumede & Mills 2009).

Typically, rural areas in South Africa - the main area of data collection for my thesis – are characterised by poor quality and access to health care services, low levels of education, high unemployment, limited infrastructure for water and sanitation, limited access to electricity due to high costs, high rates of migration, and poor transport to cover long distances between villages and to access basic health care (Kahn et al 2007; Madhavan & Schatz 2007; Thorogood, Connor, Tollman, Hundt, Fowkes & Marsh 2007). Furthermore, the return of migrants, who went to urban areas to find work, back to their rural households, is often because of terminal or chronic illness (Collinson, Tollman & Kahn 2007). Thorogood and her colleagues describe the increase of hypertension and related strokes as diet increases and social causes of stress increase.

The contemplation of life context characteristics, thus, becomes important in developing an understanding of how people respond to questions on disability and functioning. Do their responses reflect problems in their healthworlds, poor socio-economic status, or lack of social capital and

networks? If they report symptoms of common mental health disorders, including difficulties with worry, anxiety, depression, pain and fatigue, do we count this as disability? How do we interpret such statistics? Is this disability or poverty, including adverse life contexts?

2.4.5 Objective and subjective measures

Measures can be objective or subjective. Objective measures use a yardstick against which an individual's performance or state is compared and scored, or where an observation is recorded; for example,actual income, size of dwelling, and access to basic services. The person, whose wellbeing or another characteristic is being measured, does not provide a response. An outsider observes or measures. Observations, in themselves, incorporate an element of subjectivity, as different raters may observe different things, for example, level of functioning. The level of subjectivity in observations will depend largely on the nature of the observation tool. For example, rating a person's ability to walk may be measured by the time it takes to walk a fixed distance, or just by observing the person walking and rating this on a scale. The former is an objective measure, while the latter is a rated observation. Subjective or self-reportmeasures are provided by the person concerned and are determined by that individual's own perceptions. Subjective measures require the person to report onhis or her own level of income or level of functioning. There seems to be growing evidence that self-report subjective data have been shown as stable and useful. (Uppal 2006). The data collection is subjective, but about an objective level of achievement. I aim, through this thesis, to contribute to understanding these self-report measures, and, specifically, of functioning.

These objective and subjective measures should not be confused with objective and subjective phenomena, such as objective and subjective wellbeing. Subjective wellbeing (measured as satisfaction), by its very nature, is measured using self-report satisfaction or happiness. It cannot be measured objectively. Similarly, data on disability-related quality of life can be obtained using measures of satisfaction, as rated by a person,on his or her level of functioning. Objective wellbeing

is defined as 'empirically observable material conditions', and includes life expectancy, income, nutrition, employment, education and democratic participation as set out by the International Wellbeing Group (Wiseman and Brasher, 2008: 357). Income, education and life expectancy are the measures used in summary measures of development such as the Human Development Index (HDI), or a 'suite of indicators' such as the Millenium Development Goals (MDGs) and their related indicators (Wiseman & Brasher 2008: 357). These objective wellbeing conditions can be measured using objective or subjective self-report measures.

Cieza, Bickenbach and Chatterji (2008) raise a concern about the confusion between the two concepts of subjective and objective wellbeing and their measurement, with no clear delineation of each, and interchangeable use of terminology. The resulting statistics are themselves unclear.They suggest that the confusion may have arisen in part because of the use of self-report measures for both disability and quality of life. Self-reporting is subjective and seemingly at odds with the notion of measuring an objective level of functioning. It is not at odds, however, with the notion of measuring satisfaction – or providing a valuation of one's functional level. The abundant use of self-report measures in rheumatology clinics, for example, is testimony to the value of such measures in complementing other clinical assessments and laboratory tests in determining the effectiveness of interventions (Wolfe, 2002). In surveys, we ask questions on both level of functioning and satisfaction with this level (or quality of life), but the responses for both areself-report ratings. The question evaluation I conducted was on measures of level of functioning.

2.5 Conclusion

In this chapter I set out how I define disability and showed how it is related to broader concepts of wellbeing and health. All three of these phenomena are complex and require careful consideration when developing measures to collect statistics. The different components of disability give clarity on the construct being measured. Understanding the relationship between wellbeing and health provides potential explanations for how people respond to questions on disability. The discussion on

disability measurement contextualizes the measures I evaluate historically, and explains the necessity of evaluating questions prior to finalizing and fielding a survey questionnaire. Having set out the different frameworks that underpin my research question, I present the aims and objectives of my thesis.

2.6 Aims and Objectives

The factors that are likely to influence people's responses to questions on functioning and disability include, among others, question wording, cognitive processes entailed in generating a response, and the life context of a person. The aim of this thesis is to explore these factors in relation to a given set of questions (WG Short and Extended Sets and WHO SAGE) applied in South Africa nationally and, in more depth, in a poor rural area in Mpumalanga, South Africa.

The research questions of my thesis are as follows:

> What roles do question wording, question understanding and interpretation, and people's life context play in determining their responses to questions on functioning? How do the findings of this study help us to understand a) disability measurement and statistics and b) disability as a phenomenon?

The specific objectives are to explore each of the three aspects in relation to two sets of questions used to measure disability, the WG Short and Extended Sets and the WHO SAGE questions. These are elaborated on in the next chapter.

Chapter 3

Methodology

The methodology of a study is 'the theory (or set of ideas about the relationship between phenomena) of how researchers gain knowledge in research contexts, and why' (Scott & Morrison 2007: 153) and 'pertains to the science and study of methods and the assumptions about the ways in which knowledge is produced' (Grix 2004: 32). The methodological paradigms recognised in most fields of research include qualitative, quantitative and mixed methods paradigms (Johnson, Omwuegbuzie& Turner 2007). Historically, in the field of social science research, the quantitative and qualitative paradigms were, initially, very separate methodologies but gradually they became used in variously integrated ways through triangulation, leading to what is referred today as the mixed methods research paradigm (Johnson et al. 2007; Greene 2008).

The advent of journals such as the *Journal of Mixed Methods Research* in 2007, from the SAGE stable of journals, attests to the maturing of social science research, where both qualitative and quantitative methodologies are acknowledged as equal contributors to developing this field. The coining of mixed methods research as a third methodological paradigm is the culmination of the ongoing use by numerous researchers of both qualitative and quantitative methodologies for answering the same research question.This study is firmly contextualised within a mixed methods research methodology.

This thesis is about methodology, and specifically, the performance of questions used to measure disability to produce valid, reliable and cross-comparable disability statistics, with validity being the focus of my thesis. This chapter presents the methodology for researching this methodological question. As I discussed in chapters 1 and 2, care is required in the development of survey questionnaires to ensure reliable, valid and cross-comparable measures.

3.1 Research Design

For this study, I used a mixed methods approach to explore the complexity of disability measurement and statistics. Greene (2007:7) contextualises the development of mixed methods research in the fields of practical work such as education, nursing and evaluation where 'the demands of the contexts ... called for both generality and particularity. And they called for defensible patterns of recurring regularity as well as insight into variation and difference.'

Johnson and colleagues (2007: 123) reviewed a wide range of different definitions of mixed methods research and concluded with the following definition:

> Mixed methods research is the type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g. use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purposes of breadth and depth of understanding and corroboration.

These authors identify breadth as one of the themes cutting across most definitions of mixed methods research. This breadth ranges from: a) the use of qualitative and quantitative methods in one stage of the research, for example data collection, through to using it at all stages of the research; b) data collection; and c) analysis and interpretation. A further theme they identified was *why* mixing of methods is used. The major theme was that mixed methods research provides 'a fuller picture and deeper understanding' (p.122), allowing corroboration through triangulation of methods, thus enhancing the validity of findings and confidence in the results.

The aim of this study is to provide a nuanced understanding of how people interpret and respond to specific wording within the questions and whole questions. The need for detailed narratives explaining responses provided by respondents is best served by using qualitative methods,while the comparison of response profiles for different contexts and respondents is best served using a quantitative methods.

The mixing of methods in this study occurs at all stages of the research, from conceptualisation and data collection through to analysis and interpretation of the results. The mixed method approach starts by the very nature of the study, which is about quantitative measures for disability statistics viewed from a qualitative perspective to provide a detailed understanding of the measures' performance. Patterns of interpretations, obtained through qualitative methods, are used to explore the performance of the disability measures. Secondly, each interview included both standard questions and open ended topics and discussion. Thirdly, at a more specific level, responses to open ended questions were translated into numeric codes for further analysis into profiles of functioning, such as the coding applied to life context factors described below.

3.2 Overview of methodology

At the outset of my research, I was interested in understanding the factors that influence people's responses on questions about disability. To explore this, I collected data through focus groups (at a national level), individual semi-structured interviews (in a single rural locality) and in-depth cognitive interviews (in the same rural locality). The data collected looked at: a) how the wording of questions affected people's responses (focus groups), b) how people understood and interpreted questions on disability (in-depth cognitive interviews with 10 rural dwellers), and c) the life context of 69 rural dwellers and how this was associated with different response profiles on the disability questions. The methodology is divided into three separate 65data collection phases, and the measures assessed are existing questions from two sources: The Washington Group on Disability Statistics' Short and Extended Sets (Washington Group on disability Statistics 2008; UNESCAP 2010) and the WHO's SAGE questions (Sankoh 2010; Kowal et al. 2010). The timing of different phases of data collection occurred as follows: a) focus groups in February – May 2006; b) 69 semi-structured interviews May-June 2008; and c) 10 cognitive testing interviews conducted in March 2009. The presentation of the results does not follow this sequence as the 10 cognitive testing interviews are analyzed in the chapter preceding the analysis of the 69 semi-structured interviews. The reason for

this is to present and discuss findings in a progression from the word level, to the whole question, and finally to the question within a social context.

The data for this thesis were collected in part only for my thesis and in part for other projects, but all data collection was planned and undertaken or closely supervised by me. The focus groups were run for StatsSA and I was given permission by StatsSA to use part of the information for my thesis. The 69 interviews at the Agincourt Health and Population Unit (AHPU) were run subsequently to, but based on the annual census of 2006. The 10 follow up interviews were initiated by the needs of this thesis but were also used (7 of the 10 interviews) for the work undertaken by the Washington Group in the development of the Extended Set of questions.

This dual purpose of the data collection process is a common practice that ensures feasibility of such research, at the level of funding and organization, enriches the thinking behind the research process because of being part of larger projects, and, more importantly, ensures that the findings have immediate relevance and rapid uptake. Particularly, for the StatsSA work, the research resulted in the Washington Group Short Set being used in the South African Census of 2011. The data were all collected using a conceptual framework developed and implemented by me making it an appropriate set of data for my thesis.

The detailed demographic information for the 10 follow up cognitive testing interviews are presented in Appendix 5, and for the 69 interviewees in Appendix 7. The demographic information on age, sex, socio-economic status and education level highlight the fact that the respondents were predominantly, over 50 years of age, of low socio-economic status and generally with low educational achievement. While the age of the respondents was in part determined by the respondents in the AHPU census, this was congruent with the understanding that those respondents most likely to have different interpretations of survey questions to that intended by the survey developers, are older and less literate people (Miller 2003). All respondents were Shangan speaking.

The demographic information for the focus group participants is inherent in the group description (e.g. elderly people, younger adults, youth) and their socio-economic status was in part determined by the location of the group. Figure 2, presented in section 3.7.1a, presents the nature, urban/rural location and language of the groups. The participants of the rural groups were more likely to be of lower socio-economic and educational achievement than the urban groups. However, all the participants were of low to very low socio-economic status, except for the ones in group 20, which was a group of educated professionals.

3.3 Aims and objectives

As stated at the end of Chapter 2, the overall aim of this study is to investigate the role question wording, cognitive processing and people's life context play in determining their responses to questions on functioning, and how the findings of this study help us to understand disability measurement and statistics, primarily, but also the phenomenon of disability.

Specific objectives of the study are:

1. To examine the effect of question wording on responses, specifically comparing three questions: a) WG Short Set (6 questions); b) the 2001 South African Census question on disability; and c) 'Are you disabled?' This is the word level of analysis.

   The specific questions for this objective are:

   1.1 How many people respond positively (i.e. report a difficulty) on the three sets of questions?

   1.2 What are the major differences between people who are 'disabled', 'non-disabled' and 'unsure' as to their disability status as measured on the three sets of questions – WG Short Set, 2001 Census Question and 'Are you disabled?'?

1.3 How do people's descriptions of what disability is fit with their understanding of and attitudes on disability? And, how they respond on the questions relative to their understanding?

2. To examine the nature of respondents' interpretation and understanding of the questions as evidenced by the explanations they provide for their responses. This is the question level of analysis.

   The specific questions for this objective are:

   2.1 What questions were correctly interpreted (i.e. as intended by the question developers)?

   2.2 What range of interpretationswas provided by the respondents?

   2.3 What questions were most difficult for respondents to understand and respond to?

   2.4 What reasons were given for different interpretations?

3. To examine the relationship between people's responses and their overall life context and what they understand as being important in their lives. This is the contextual level of analysis.

   The specific question for this objective is:

   3.1 What typical response profiles, if any, were found for questions on disability measurement?

   3.2 What typical life context factors were described by respondents?

   3.3 What is the association between response profiles on the disability questions and the life factors?

3.4 Structure of the methodology

The methodology is presented in a series of sections that start with general concerns that are generic to all three phases of data collection, followed by specific aspects pertaining to each of the three results chapters (chapters 4, 5 and 6).

3.5 Disability measures

This study does not develop measures but investigates the performance of existing sets of questions on disability. Two sets of questions were used in the study either alone or in combination. The two main sets are those from the Washington Group (Short and Extended Sets) and the WHO questions for describing health states as used on the SAGE short version survey. Two additional questions were used in the focus groups. These were the South African Census 2001 question on disability and the question 'Are you disabled?'

The questions are presented in Appendix 1, 2 and 4 respectively and are described briefly here. In addition, a separate card for each of the question sets is available in a pocket on the back cover for ease of reference for the reader. The red card presents the WG Short Set and South African Census 2001 questions, the green card the WG Extended Set, and the yellow card the SAGE questions.

3.5.1 Washington Group Short Set

The Short Set comprises six questions each covering functioning in one domain. The domains are seeing, hearing, mobility (lower body – walking or climbing stairs), cognition (remembering and concentrating), self-care (washing and dressing) and communication in one's usual language. There are four response options on a scale of no difficulty, some difficulty, a lot of difficulty and unable to do. Miller, Mont, Maitland, Altman &Madans (2010) describe the structured cognitive testing process undertaken on the WG Short Set questions, showing that the questions seem to provide good measures of disability in the countries where testing was carried out. This testing used a very structured approach with a standard questionnaire, rather than in-depth cognitive testing interviews, to facilitate a common methodology across a number of different countries. South Africa was not part of that testing round. While the WG Short Set has been adopted by the WG and its parent body, the UN Statistical Commission, it remains a legitimate exercise to test these questions in further countries and contexts, as is done in this study.

3.5.2 Washington Group Extended Set

A continuing aim of the WG is to develop a set of extended questions to be used as a module on a survey or as part of a dedicated disability survey. This work is currently being completed.A set of questions were developed and have undergone cognitive and field testing predominantly in the Asia-Pacific Region (UNESCAP2010). These questions formed the basis of the final set of interviews carried out in March 2009 for this study. These interviews also contributed to the international testing of the questions and were included in that analysis (although only five of the ten were included in the international analysis).[21] These questions will be referred to as the WG Extended Set questions. This extended set incorporates the Short Set six questions, but has additional questions on the domains of learning, affect (anxiety and depression), pain and fatigue. The ten domains also include more than a single question per domain in order to obtain more detailed information on functioning in these different domains. In my analysis, I do not include the domain of learning, as initial findings of the WG/UNESCAP international study on the cognitive and field testing of these questions (UNESCAP 2010) showed that they performed poorly, with very little congruency between the question intent and the interpretation by respondents. The questions require significant revision and further testing. I therefore present nine of the ten domains, but because of splitting up the Affect domain into Anxiety and Depression, I remain with ten sets of questions.

3.5.3 SAGE Health state description questions:

Despite the SAGE questions not having been tested cognitively, they have been used on a series of international survey platforms (Ustünet al. 2003a, b; Kowal et al. 2010), as described in Chapter 2. As already noted, the SAGE questions were used specifically in one of the sites included in my study – the Agincourt Health and Population Unitsite in Mpumalanga, South Africa. The questions were applied as part of the Agincourt Health and Population Unit (AHPU) in the 2006 annual census as

[21] The reason for this was purely technical as the time available was too limited to allow the information from all 10 interviews to be captured in the required database.

part of the Adult Health module. I only included the questions on basic activities, as set out in Appendix 4.

3.5.4 Additional questions

Two additional questions were the question used in the South African Census of 2001 (StatsSA 2005), and a 'Are you disabled?'. These were included to provide, firstly, a comparison between the WG Short Set and the Census 2001 question for StatsSA research on census content areas, and, secondly, to provide some comparison between using the terms 'difficulty' and 'disability'.

The StatsSA question used in the 2001 Census was the following:

> Do you have any serious disability that prevents your full participation in life activities (such as education, work, social life)? *MARK ANY THAT APPLY.*
>
> 1. None
> 2. Sight
> 3. Hearing
> 4. Communication
> 5. Physical
> 6. Intellectual
> 7. Emotional

3.5.5 Combinations of questions

- The WGShort Set, Census 2001 question and 'Are you disabled?' were used in the focus groups, run as part of the StatsSA census content research in 2006.
- The WG Short Set, SAGE questions and 'Are you disabled?' were used in the 69 semi-structured interviews undertaken in Agincourt in May/June 2008.

Table 1 summarises the different sets of questions and their combinations used in the different data collection phases.

3.5.6 Comparison of the WG and SAGE questions

The two sets of questions, WG and SAGE, are not identical. Nevertheless, they share sufficient characteristics to situate both sets of questions in the current approach to measuring disability. Both

sets i) have as their underlying framework the ICF and its principles;ii) use the term 'difficulty' and not 'disability'; and iii) use a scale of response options rather than a mere 'yes/no' response format. However, this does not mean that they perform exactly the same. My study only uses the SAGE questions in creating profiles of functioning to analyze in association with life context factors. The wording and whole question evaluations were only undertaken for the WG Short and Extended Sets.

Table 1: Summary of question set combinations in the three phases of data collection

	Combination of questions				
Data collection phase	WG Short Set	WG Extended Set	SAGE	Census 2001	'Are you disabled?'
21 Focus groups (national)	X			X	X
69 semi-structured interviews (Agincourt)	X		X		X
10 cognitive testing interviews (Agincourt)	X	X			

The SAGE questions do not cover all the same domains as the WG Short Set. The domain of hearing is not included in the SAGE, but it is in the WGShort Set.[22] The SAGE questionsinclude the same domains (plus additional ones) as the WG Extended Set. The one important difference is that, in the SAGE, the domain of 'sleep/energy' is used while in the WG Extended Set the domain of 'fatigue' is used.

While, ideally, a consistent set of questions should have been used in all the data collection, the study contexts and timing made this impossible. The focus groups aimed to test the WG Short Set for

[22] The omission of the hearing domain in the SAGE dates back to the development of the WHS questionnaire where analysis of the Multicountry study data indicated that the hearing domain did not add any explanatory value to the identification of health states (Murray and Evans, 2003).

StatsSAat a national level (Schneider, 2009; Schneider et al, 2009).The AHPU used the SAGE question as part of an international study on ageing overseen by WHO (Sankoh 2010; Kowal et al. 2010), which gave me access to respondents who had answered these questions.The WG Extended Set wereevaluated, in a sub-group of the AHPU respondents on the SAGE, as part of aninternational study on improving disability measures, a joint initiative of the Washington Group on Disability Statistics and the UNESCAP's Statistics Division (UNESCAP 2010). I took advantage of both of these studies and added to them with the three phases of data collection described above. Furthermore, the WG Extended Set was not available at the time of doing the 69 semi-structured interviews. The advantages of situating this thesis research in these other studies outweigh the relatively small differences between the WG and SAGE questions, relative to questions asking about being 'blind, deaf, crippled or mentally retarded'.Chapter 6 presents data to show that there is reasonably good congruence in the domains of difficulty identified by the WG Short Setversus the SAGE.[23]

3.6 Methods

I used both qualitative and quantitative methods to explore the research question. The qualitative methods include focus group discussions, semi-structured interviews and question evaluation, through cognitive testing interviews. The quantitative methods include standard questionnaires – one for the focus group participants, one for those 69 people who also participated in semi-structured interviews, and one for the ten participants in the in-depth cognitive testing interviews carried out in March 2009.

All interviewees and all participants in the focus groups were aged 18 years and older and all responded for themselves. No proxy interviews were carried out. The design of this study was

[23]This does not deter from the fact that there are some significant differences in the questions asked about the more complex domains of functioning. But these are not relevant for this study, which focused on the basic domains of functioning.

exploratory in nature and combined a series of methods and data sets (see Table 1 above for a summary of the data sets used). They are presented below.

Focus group discussions included a standard questionnaire administration prior to the focus group discussion. The purpose of these focus groups was to test the WG Short Set questions for use in the 2011 census in South Africa. The administration of the questions prior to the focus groups discussion gave the participants an opportunity to answer the questions and become familiar with the questions to be discussed in the group. These questions are presented in Appendix 1, and included the WG Short Set, Census 2001 question and 'Are you disabled?'. Focus groups are a well-recognised method for collecting information on various topics and allowing for debate, reflection and divergent views to be expressed by the group in a facilitated manner.

Semi-structured interviews included a standard questionnaire followed by some open ended questions. This questionnaire included the WG Short set coupled with basic domain questions from the SAGE. These are presented in Appendix 4a and b. The interviews were semi-structured to allow for a larger number of interviews in a given time and budget to be completed. The benefit of using open ended questions and probes is the lack of structure imposed on the respondent's narratives.

Cognitive testing interviews are the technique developed within the CASM approach discussed in Chapter 2. These included standard questions and a discussion on respondents' understanding of each of these standard questions and reasons for their responses. The interviewer asks the question being evaluated, and follows the response given with probes to elicit narratives that explain and set out the respondent's interpretation and understanding of the question. The questions evaluated were the WG Extended Set and are presented in Appendix 2.

The use of these methods in relation to the three objectives is presented in Table 2, where I use inverted commas ('…') when referring to the disability status of these groups (disabled, unsure and

non-disabled). I allocated this status *a priori* as a method of categorizing the groups to analyze for differences between the three different statuses.

3.7 Data sources

As summarised in Table 3, there are three main sources of data in this thesis:

1) 21 focus groups run in different settings nationwide
2) 69 semi-structured interviews undertaken in Agincourt, a rural area in northeast Mpumalanga province in South Africa and where the AHPU is situated (see below for more on the AHPU).
3) Ten cognitive testing interviews with participants selected from the 69 respondents for the semi-structured interviews in Agincourt.

The findings in this thesis provide useful information for South African use, and add to the growing body of international findings. Each data source is discussed individually.

Table 2: Summary of Data sources, geographical location and data collection

Data source	Geographical Location	Data of collection
21 national focus groups with adults	National – 8 provinces, different languages and population groups	February – April 2006
AHPU Census 2006 – adult health module (for selection of participants only)	All 20 villages in Agincourt HPU	July – October 2006
69 Semi structured interviews	5 villages in AHPU	May – June 2008
10 cognitive testing interviews	3 villages in AHPU	March 2009

Table 3: Description of methods and their relationship with specific questions

Objective	Source of data	Specific questions linked to data Source
1. The effect of question wording on responses, specifically comparing three questions: a) WG Short Set (6 questions); b) the 2001 South African Census question on disability; and c) 'Are you disabled?' This is the word level of analysis. This objective is the focus of Chapter 4.	1.1 *21 focus groups* • Adult respondents (18 years and older) • 9 focus groups with 'disabled' respondents • 6 focus groups with respondents with 'unsure' disability status • 6 focus groups with 'non-disabled' respondents • Total = 185 focus group participants • Direct respondents 1.2 *69 semi structured interviews in AHPU* (see objective 3 for more detail)	1.1. How many people respond positively (i.e. report a difficulty) on the three sets of questions? 1.2 What are the major differences between people who are 'disabled', 'non-disabled' and 'unsure' in how they respond to the three sets of questions – WG Short Set, 2001 Census Question and 'Are you disabled?' ? 1.3 How do people's descriptions of what disability is, fit with their understanding of and attitudes on disability, and their responses on the WG Short Set questions?
2. The nature of respondents' interpretation and understanding of the questions as evidenced by the explanations they provide for their responses. This is the question level of analysis. This objective is the focus of Chapter 5.	2.1 *10 cognitive testing interviews* • Adults (18 years and older) • Selected from 69 respondents on semi-structured interviews • Criteria for selection: range of ages and range of responses on the semi-structured interviews • Respondents selected from 3 villages only	2.1 What questions were correctly interpreted (i.e. as intended by the question developers)? 2.2 What range of interpretations were provided by the respondents. 2.3 What questions were most difficult for respondents to understand and respond to?
3. The relationship between people's responses and their overall life context and what they understand as being important in their lives. This is the contextual level of analysis. This objective is the focus of Chapter 6.	3.1 *69 semi structured interviews in AHPU* • Adult respondents (18 years and older) • Selected from 5 of the 21 AHPU villages • 100 respondents selected (20 per village) using selection criteria (see below in main text) from 2006 AHPU Census sample of respondents who completed SAGE short version module) • Standard questionnaire (WG Short Set + selected SAGE Short version questions) followed by a series of life context questions in open ended format. • Direct respondents	3.1 What typical response profiles, if any, were found for questions on disability measurement? 3.2 What typical life context factors were described by respondents? 3.3 What is the association between response profiles on the disability questions and the life factors? 3.4 What is the association between response profiles on the disability questions and the life factors profiles ? 3.5 How do people's descriptions of what disability is fit with their understanding of and attitudes on disability, and their responses on the WG Short Set questions?

3.7.1 The focus groups

Statistics South Africa (StatsSA) commissioned the Human Sciences Research Council (HSRC) to conduct a series of focus groups to develop and test questions for use in the 2011 Census. I was the principal investigator for this research, and was responsible for the full research process, from writing the research proposal, developing the interview guide and questionnaires, running or observing most of the groups, analysing the data and writing the report. The project was documented in a report for StatsSA (Schneider &Couper 2007) and the results were published in a journal article (Schneider, 2009). The project included 26 focus groups, of which five groups were of parents of children (two of parents of non-disabled children and three of parents of disabled children). The remaining 21 groups were with adults who responded for themselves. I only used the 21 adult focus groups for my study. StatsSA gave permission for these data to be used for the purpose of this study.

The focus groups allowed for a productive exploration of the issues related to people's understanding of the questions proposed for Census 2011 as well as the notion of disability and difficulty. The qualitative methods were complemented by the administration of a questionnaire to collect basic demographic information on the participants, and their responses on the proposed Census 2011 questions. The use of the questionnaire also allowed the introduction of the questions to the participants prior to the discussion on these very questions.

a) Distribution of the focus groups

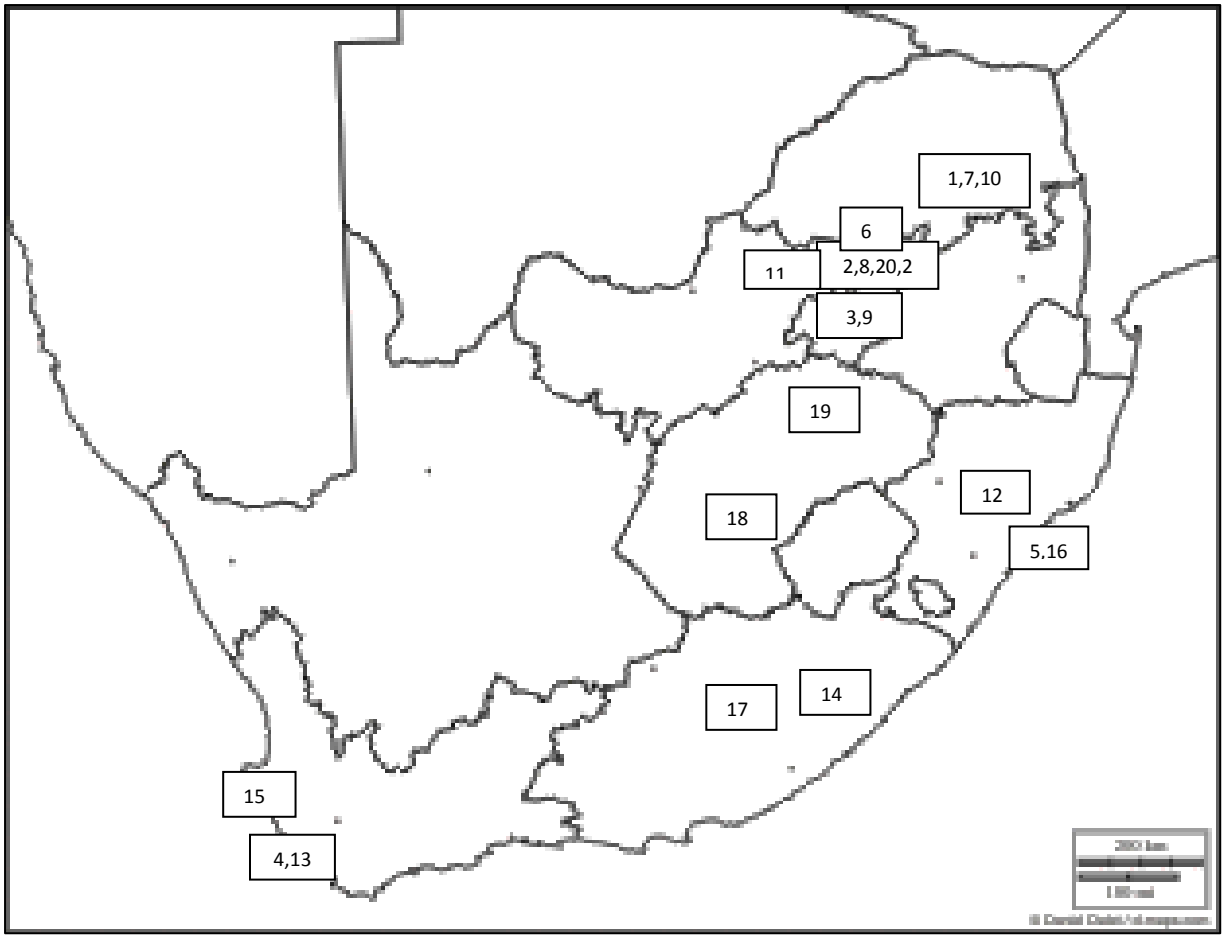
In deciding on the distribution of the focus groups, a number of stratification variables were applied. As the Census questions are to be applied to the whole population and not only to people who clearly identify themselves as disabled, the focus groups included a cross section of people determined by me as thedisabled and non-disabled sectors of the population.

While this allocation of disability status may seem to be putting the cart before the horse, given that the aim of this thesis was to assess measures of disability, it was done according to commonly held perceptions of who is disabled. The results of the focus groups vindicated this allocation, showing clear differences between the three types of disability status. This is discussed further in Chapter 4.

The stratification variables included the following, as applied to the 21 adult focus groups:

- *disability status as 'disabled', 'non-disabled' and 'unsure'*: 'disabled' people clearly identify themselves as disabled for one or more reasons,'non-disabled' people do not identify themselves as disabled, and 'unsure' are people with chronic conditions, such as asthma, hypertension, HIV, or diabetes, or are elderly, and who might or might not identify themselves as 'disabled'. This status was allocated to the groups *a priori,* with no consultation with people as to how they would, in fact, identify themselves. The questionnaire administered prior to the start of the focus group included a questions 'Are you disabled?', which was used in the analysis to correlate this *a priori* allocation of disability status to that taken on by the participants themselves.
- *Geographical location*: urban and rural
- *Type of disability and range of chronic conditions*: visual, hearing, and physical impairments, psychiatric illness, head injury, chronic illness, HIV/AIDS, old age, youth, adults, or not disabled (or not known to be disabled).
- *Provincial spread*: all provinces were included except for the Northern Cape.
- *Population group and language spread*: English, Afrikaans, Tsonga, Tswana, Zulu, Xhosa, Swati, and Sotho were used in different focus groups. Each group used only one language.

This resulted in an allocation of 21 groups, as shown in Figure2.



Adapted from http://d-maps.com/carte.php?lib=south_africa_map&num_car=773&lang=en

Figure 2: Distribution of the 21 focus groups with adults

Key to Figure 2:	
1 = Visual Imp (rural) (Shangaan)**	12 = Older people (urban) (Zulu)***
2 = Visual Imp (urban) (English)*	13 = People living with HIV/AIDS (urban) (Xhosa/English)***
3 = Hearing Imp (urban) (English)*	14 = People living with HIV/AIDS (rural) (Xhosa)***
4 = Deaf (urban) (Sign Language)***	15 = Non-disabled adults (Coloured community) (Afrikaans)***
5 = Physical Imp (urban) (English)*	16 = Non-disabled youth (urban) (English)**
6 = Physical Imp (rural) (Tswana/Sotho)	17 = Non-disabled youth (rural) (Xhosa)***
7 = Psychiatric illness (rural) (Shangaan)**	18 = Non-disabled adults (urban) (Southern Sotho)***
8 = Psychiatric illness (urban) (English/Afrikaans)*	19 = Non-disabled adults (rural)(Southern Sotho)***
9 = Chronic illness (urban) (English)*	20 = Non-disabled adults (urban) (English/Afrikaans)***
10 = Chronic illness (rural) (Shangaan)**	21 = Brain injury (urban) (English/Afrikaans)*
11 = Older people (rural) (Tswana/Sotho)***	

b) Focus group questionnaire and discussion guide

The two instruments developed for this researchwere the questionnaire administered individually prior to the discussion, and the discussion guide for the group discussion(Appendix 1). These were developed to cover all the aims of the StatsSA research. For my thesis I only used the responses to the questionnaires and the discussion on disability versus difficulty.

i. Questionnaire:

The questionnaire asked for basic demographic information on the focus group participants, and recorded their responses on three sets of questionson disability: The WG Short Set, the Census 2001 question and 'Are you disabled?'. The standard StatsSA Census questions for education, marital status and employment were included as part of the background information for each participant.

Questionnaire translation was undertaken in all official languages except for Venda (no groups were run in Venda). It was also administered using South African Sign language to the Deaf participants by a Deaf facilitator, with the assistance of an interpreter and hearing research assistant. The translation of the questions was undertaken in a group context, with translators from the different languages discussing and then translating the concepts. The translations were checked by a third person. Three of the languages (Swati, Xhosa and southern Sotho) were translated by people using the completed translations in related languages as guidelines. For Swati and Xhosa the translator used the Zulu completed translation as a guide,and for Sotho the Northern Sotho and Tswana translation were used.

The questionnaire was administered in different ways, depending on the level of literacy of the participants. Where the participants were sufficiently literate, they were given the questionnaire to read and complete by themselves, or the facilitator read the questions and individuals marked their own responses. Where the participants were not sufficiently literate, the questionnaire was administered by the focus group facilitator, note taker, or observer to each individual prior to the start of the group discussion. In groups of blind or partially sighted individuals, the facilitator read the questions, and the observers and note taker assisted the participants to mark their responses.

The Deaf participants had the questionnaire administered using sign language and they marked their own responses.[24]

ii. Discussion guide

The discussion guide was developed with the Terms of Reference for the full StatsSA study in mind. The topics of the guide relevant for this thesis were the following:

- Eliciting reactions from participants on the questions in the questionnaire in terms of difficulty in understanding, embarrassment, sensitive topics, time reference and ability to answer within those time periods, or any other comments,
- Conceptualisation of the notion 'disability' generally and in contrast to the notion 'difficulty'.
- Relevance of the content covered in the questions and need for further questions.

The approach was used to elicit discussion about the participants themselves and their reaction to various scenarios of people with or without difficulties. This approach allowed for investigating individuals' responses to the same scenarios. The scenarios were about adults for the adult groups and about children for the parent groups.

The discussion guide was not translated into the official languages prior to running the groups. I trained the facilitatorsto understand the content of the guide and undertake the translation as they ran the groups.

c) Data collection procedures, transcriptions and data entry

The recruitment of the 'disabled' participants was done through different organisations of people with disabilities, such as the National Council for the Blind and Disabled People South Africa. The participants for the 'unsure' groups were recruited through staff at a local urban hospital for people

[24]The group of Deaf participants had a Deaf facilitator. In addition an interpreter was present who interpreted into spoken language for the observer/note taker. The interpreter's verbalizations were audio recorded. When required, the note taker provided guidance to the facilitator through the interpreter.

with chronic illnesses, and a person from a disabled persons' organisation was employed to recruit participants with chronic illness in a rural area. An HIV/AIDS project run by Médecins Sans Frontières in Lusikisiki, Eastern Cape, and the Treatment Action Campaign in Cape Town, were asked to assist in recruitment for the two HIV/AIDS groups. Only people with HIV/AIDS who were open about their status were recruited, to avoid issues of confidentiality. The remaining groups were recruited from the general population by paid recruiters in the selected areas. The target for each group was eight participants and the number ranged from six to eleven participants. The average size of the groups was eight to nine participants.

The participants were given refreshments before, during or after the group, and were paid an honorarium of R100 each. Any transport costs incurred were also reimbursed.

The groups were held in a quiet room available at an accessible location, and the discussion was audio recorded using two audio recorders.[25] The note taker took notes of the proceedings, to provide back up to the audio recording. The Key to Figure 2 shows which groups I facilitated (*), observed (**) or did not observe (***). I was the facilitator for six groups and observed four.

The participants were all asked to complete and sign the consent form prior to participating. If a participant was not able or unwilling to sign, the facilitator signed as witness to a verbal agreement. The aims and objectives of the project, process of the discussion and the role of the HSRC and StatsSA were explained verbally, and the information sheet, with all this information, was given to the participants to take home. The information sheet also had a phone number of the project coordinator,to be used if the participants had any issues to discuss after the group had been completed.

[25] The focus groups were recorded on tape recorders, and the Agincourt interviews were all recorded on digital audio recorders.

The groups allocated as English or Afrikaans includedparticipantswho were able to participate in either of these languages. These groups were often mixed in relation to population group and included White, Indian, Coloured and Black participants. Even after 17 years of democratic rule, the legacy of apartheid remains, and requires disaggregation of data by these four population groups, in order to illustrate differences resulting from the social contexts of each of these population groups. I ensured that the groups included all four population groups.

The audio recordings were transcribed into the original language and translated into English. Names of the participants were not used on the transcriptions. The responses to the questions on the questionnaires were captured onto SPSS for calculating frequencies and cross tabulations.The transcribed texts were entered into Atlas-ti and coded thematically. The themes identified by the discussion guide were used as the starting point for coding, and themes emerging from the transcripts were added to these. For example, the difference between 'difficulty' and 'disability' was one of the themes identified in the discussion guide, while different ways of understanding disability were themes that emerged from the transcripts.

3.7.2 The Agincourt/AHPU interviews

The research team focusing on Adult Health the Agincourt Health and Demographic Surveillance site (also known as the Agincourt Health and Population Unit- AHPU)[26] included, as part of their brief, research on adult functioning. As part of this ongoing work, the AHPU administered the short version of an adult health and functioning module from the Global Study on Ageing (SAGE) (Sankoh 2010; Kowal et al. 2010), as part of the 2006 annual census round, to adults 18 years and older with an oversampling of respondents 50 years and older to meet the requirements of the Global Study on Ageing (SAGE).

[26]The name Agincourt and acronym APHRU will be used interchangeably when referring to this data collection site.

The AHPU, as described by Kahn and colleagues (2007) is located in a rural sub–districtof Mpumalanga Province in north eastern South Africa. The site comprises 21 villages and has a population of just over 70 000. The area is densely populated with 174 persons per square kilometre. The majority of the population are Shangaan speaking, including Mozambican nationals, who migrated into a number of the villages to escape the war and conditions of poverty in Mozambique. The villages vary in size and economic conditions, within a narrow range at the lower levels of economic status.

Infrastructure is limited although there are efforts being made by the government to improve access to electricity, water and sanitation. Sanitation is basic with little formal systems, and piped water is provided through communal taps. Electricity is expensive and only few households can afford it. The roads are mostly gravel and the main transport system is the minibus-taxis. There is a primary school in each village and several high schools in the area. Rainfall is unpredictable and plots of land too small for effective subsistence farming. There are high levels of unemployment leading to many people seeking work outside of the area, albeit temporarily (Kahn et al. 2007).

The disease profile of Agincourt is a combination of high HIV seroprevalence, other infectious diseases such as acute diarrhoea, malnutrition, accidents and violence, non-communicable diseases such as Type II diabetes and, in particular, cardiovascular disease (Kahn et al 2007; Thorogood et al. 2007; Tollman & Kahn 2007).This description is an example of the health transition discussed in Chapter 2. This in a context of limited access to health care and, in particular, for the management of chronic illness (Tollman & Kahn 2007).

The households in the AHPU are classified according to socioeconomic status using a relative index based on a series of questions on household assets. The classification ranges from low to high (Kahn, Collinson, Tollman, Wolff & Garenne 2003). High socio-economic status, therefore, is a relative measure and only means households with a high status are better off than other households in the

area classified as low socio-economic status. But they remain low socioeconomic status households relative to the whole of South Africa.

Research by the AHPU started in 1992 and, in 2002, it was formally recognised as a Medical Research Council/ University of the Witwatersrand Rural Public Health and Health Transitions Research Unit (Agincourt). The aim of the AHPU was 'to introduce and evaluate innovative decentralized and primary care-oriented health programmes' (Kahn et al. 2007:9). The site comprises an administrative sub-district, and work focuses on primary health care in close collaboration with local health services. A further aim of the AHPU was to collect data on the population within the catchment area, to inform the provision of health care services.

The Agincourt site provided an advantageous context from which to do the research. The existing research infrastructure facilitated the entry into and collection of data at the village level, saving time and contextualising the research for the participants as coming from 'you Wits people'.[27] In addition, the AHPU provided me with the Census 2006 data on the adult health module, which included the SAGE questions on health states.

At an administrative level, the provision of support structures were invaluable in finding research assistants, organising employment contractual arrangements, and administering payment of their salaries. The funding was provided by an external source and deposited into the AHPU account. This academic and administrative support ensured that the research was able to proceed easily and efficiently.

a) Data sets from Agincourt

Based on a brief review of the census SAGE results from the 21 villages, I selected five villages for my data collection. From these five villages I selected respondents (all adults) who had completed the

[27] The University of the Witwatersrand is the academic institution in which the AHPU is located and is commonly referred to as 'Wits'.

SAGE module in the 2006 AHPU Census. Two data sets were collected from these respondents – the first was a set of semi-structured interviews with 69, and the second was a series of ten in-depth cognitive testing interviews with a subset of the 69 respondents. These two sets of interviews are described below.

i. Semi-structured interviews in five villages:

Of the 100 respondents selected from the SAGE respondents in the 2006 census, 69 interviews were realised. These interviews were conducted in May and June of 2008 by two Shangaan speaking fieldworkers, whom I trained and observed. While I can understand some Shangaan, this understanding is limited in relation to detail and nuances. However, by observing over half of the interviews, I developed a sense of the type of responses and issues raised by respondents. I noted that the respondents were generally willing to respond to the questions, and were able to engage with the interviewer. The instruments used for the semi-structured interviews are presented in Appendices 5a and 5b.

ii. In depth cognitive testing interviews:

As a follow-up to the original semi-structured interviews, further interviews were carried out with ten respondents in March 2009. Nine of these respondents had been interviewed in May/June 2008, and one was a person who provided an additional perspective of having epilepsy. The focus of these interviews was a cognitive interview to evaluate the WG Extended Set of questions on disability and contributed to the international work of the WG.

These interviews consisted of the following:

- The WG Extended Set of questions provided the standard questions for these interviews. Each question was posed and the response noted,followed immediately by a series of probes to elicit a narrative from the respondent, explaining his or her response. This was a 'thinking aloud' process (Miller & Willson 2009). Respondents were also asked to explain what they understood by

various terms such as depression, about the impact of any difficulties on their daily activities, and whether any difficulties they had were because of a health problem or something else. This probing process provided narratives that explained how the questions were understood and interpreted. The probes used included:

  - Why did you answer in that way?
  - What were you thinking about when you gave that answer?
  - That's interesting, tell me some more.
  - Please, can you clarify or explain your answer?
  - Can you give me some examples of what you mean?

- A series of open ended questions were asked either before or after the cognitive testing interview, depending on how the interview was initiated,covering topics such as social networks (family and friends), the type of community activities available in their village, their main source of income, and what they considered to be the most important thing in their lives.
- I undertook these interviews with the assistance of an interpreter. While this created a fragmented interview process at times when the interpreter was translating responses, it did allow me to retain relative control over the interview and delve in detail into specific issues as they arose.

The instrument used for the in-depth cognitive interviews is presented in Appendix 2.

b) Translation of SAGE and WG Extended Set questions

The SAGE Short version used in the census of 2006 was translated by the AHPU staff prior to the census in 2006. This translation was used in the May/June 2008 interviews. The additional questions from the WG Short Set were translated when tested originally for StatsSA in the focus groups, described above. The translation was revised by the research assistants before going into the field for the May/June 2008 semi-structured interviews. This allowed forthe interview content to be sufficiently familiar and easy to read by the interviewers.

Research assistants translated the interview guide for the semi-structured interviews. As part of their training, we discussed the intent of each question and they then translated these and checked each other's translation.

For the in-depth interviews in March 2009, the questions already used were retained. The additional questions were translated by two Shangaan speakers in Pretoria and the translation was checkedby the research assistant who also interpreted in Agincourt prior to conducting these interviews. Many of the translation issues that arose related to dialect differences in different parts of northeast South Africa.The final translation was based on Shangaan used in the Agincourt area.

c) Selection of villages

Figures 3 and 4 situate the AHPU within South Africa and show the spread of villages within the research site.

Of the 21 villages in the Agincourt study area, five were selected for the study. The criteria for selecting these villages ensured variation in size of villages (larger and smaller ones); ones with predominantly South African nationals and others with predominantly Mozambican ones; and a range, albeit limited, of socio-economic conditions across the villages.

The poorer villages consisted of mud hut dwellings with thatched roofs, communal water pipes where people fetched water in large drums using wheelbarrows. These poorer villages were situated furthest away from the main Agincourt site office. The less poor villages had more brick and tin roofed dwellings, with a few dwellings having water on their property, in addition to the communal water pipe. None of the villages had flush toilets.

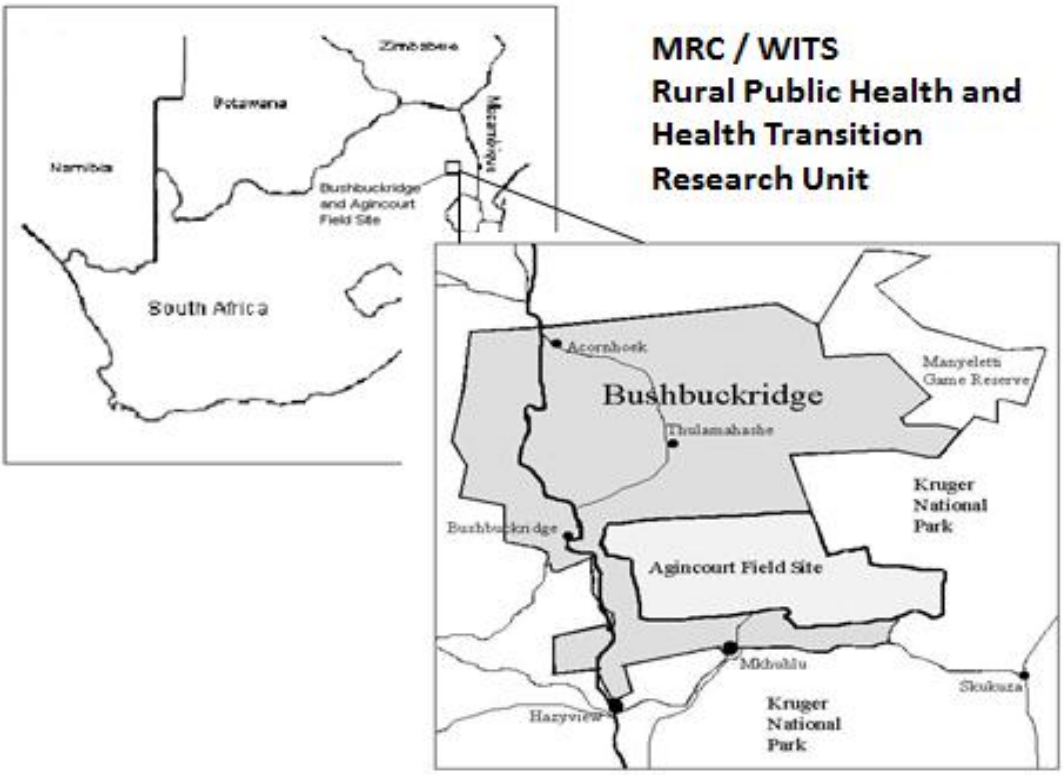


Figure 3: Geographical location of the AHPU in South Africa[28]

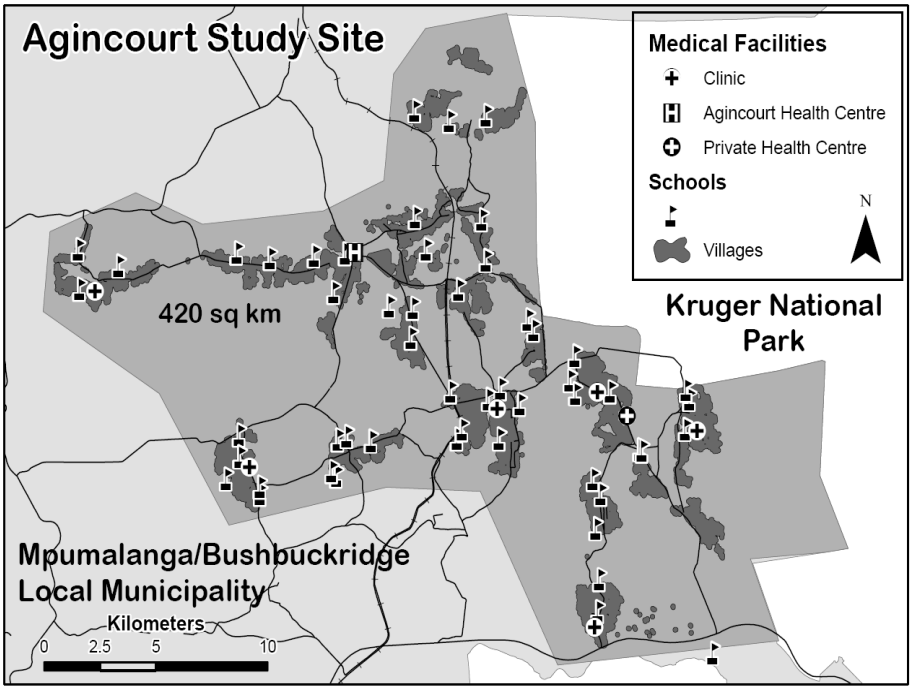


Figure 4: Distribution of 21 villages within the AHPU

[28] Permission from the AHPU to use figures 3 and 4 is gratefully acknowledged.

Most dwellings had some land for cultivating corn and vegetables, and there was a range of livestock, with better households having cows, goats and chickens, while the poorer ones having only a few chickens.

d) Selection of individuals for semi-structured interviews (May/June 2008)

The sample size of 100 individuals was chosen to provide a range of difficulty responses across different levels of severity (as measured on the SAGE short version), a manageable number of interviews, and would allow for replacement of individuals that were not found, refused to take part or had died since the 2006 census. The aim was not to obtain a representative sample for statistical purposes. Twenty adult respondents were selected from each of the five villages according to the following criteria:

- Adult 18 years or older
- Living in one of the villages selected
- Having completed the short SAGE questionnaire in the 2006 annual census.

A further stratification of the selection was done on the basis of the SAGE responses given in the 2006 Census round. The stratification aimed to provide five categories[29] of respondents, those with:

- No difficulty
- Mild difficulty
- Moderate difficulty
- Severe difficulty
- Extreme difficulty/cannot do

[29] The SAGE questions use five response options compared to the four used by the WG Short and Extended Sets.

The selection was done electronically from the Census 2006 data set, with the determined definitions applied for each category or strata. These definitions are provided in Appendix 3.

For each of the five severity categories listed above, four respondents were selected from each village, with equal distribution by sex, age and socio-economic status (SES). If there were not enough respondents in one village to fill the required N = 4 for each cell, a respondent from an adjacent cell was selected to make up the 20 respondents per village. While the selection of the villages was purposive, the selection of the individual respondents was more structured to ensure a good spread of respondents. As indicated earlier, a total of 69 interviews were completed out of the 100 selected respondents.

e) Selection of respondents for ten in-depth interviews of March 2009

The ten respondents for the cognitive testing interviews were selected to ensure a range of respondents – older and younger, with different degrees of difficulties and from different villages. In addition, I selected those respondents who had been willing to participate and who provided generally more detailed narratives in their initial interviews. Ten respondents in three villages were purposively selected.

f) Transcription and translation of interviews

For the 69 semi-structured interviews undertaken in May/June 2008, the research assistants, who had conducted the interviews, translated their own interview audio recordings. In order to check for quality, 10% of these were retranslated by a third native speaker of Shangaan, who also undertook the data entry from the questionnaires and typed the transcripts of the interviews. The differences between these double transcribed interviews were not substantial.

While the two research assistants had no particular training in transcribing and translations, the advantages of using them was their familiarity with the interview content. The first few interviews were transcribed initially into Shangaan, followed bytranslation into English. However, once it was

clear that the research assistants felt confident in transcribing, they transcribed and translated directly into English. This allowed the time taken to complete the 69 transcriptions to be significantly reduced.

For the ten cognitive testing interviews done in March 2009, the use of an interpreter allowed me to have more control over the direction and detail of the interview. As explained earlier, the impact of this approach was to create at times a fragmented interview. However, the benefits of allowing me to understand and direct the interview outweighed, in my opinion, this limitation. The length of the interviews (on average around 70 – 90 minutes) allowed the respondent, interpreter and myself to develop a rapport and minimise the impact of the fragmentation. My knowledge of Shangaan, albeit limited, did allow me to communicate directly on a number of points, which also improved this rapport. The benefits of having the interpreter was to ensure I did not miss the nuances of what respondents said. The audio recordings were transcribed and translated into English by the two research assistants in Pretoria, who had undertaken the original translations. Three of the interviews were translated a second time to check for consistency, which proved to be good. The original translation by the interpreter during the interview (and captured on the audio recording) provided a further translation check.

3.8 Data analysis

The different data sources called for different data analysis strategies. These are discussed individually.

3.8.1 Focus group data

The focus groups yielded both questionnaire data and focus group discussions. The data from the questionnaire were captured onto SPSS (Versions 12.0 and 17.0) and analyzed using basic frequencies and cross-tabulations, with various recoding of variables. For example, absolute age into age categories, different cut-off points for responses and composite scores for all questions were usedto give high and low prevalence estimates. The results are presented using percentages.

The Census 2001 question wasanalyzed using a composite score of positive responses[30] on one or more of the listed options except for the 'none' option. Each individual was counted only once, no matter to how many domains they gave positive responses.

The WG Short Set analysis followed the analysis put forward by the Washington Group (Washington Group 2005). Three cut-off points were calculated: D1, included all positive responses ('some difficulty', 'a lot of difficulty' and 'unable to do'); D2 included only responses of all 'a lot of difficulty' and 'unable to do'; and, D3 included only the 'unable to do' responses. Thus D1 gives larger estimate than D3, with D2 somewhere in between. Only D1 and D3, were used to simplify the analysis.

The analysis compared the WG Short Set, the Census 2001 questions, and 'Are you disabled?'. Responses to individual questions and the computed composite scores for all the questions were analyzed. Cross tabulations were run for the responses from the three different groups of disability status ('disabled', 'unsure' and 'non-disabled') to allow for comparison of these responses. The responses provided to the three different questions ('Are you disabled?', Census 2001 question, and the WG Short Set) were compared across the groups.

The qualitative data were analyzed thematically using the computer software Atlas-ti (Scientific Software Development GmbH n.d.). The transcripts were thematically coded and the consistency of responses were analyzed across the 21 groups. Overall patterns of response for the participants, stratified by allocated disability status, were compared. The themes were a) derived from the topics covered in the focus group discussions, and b) those that emerged from the discussions. Examples of some of the themes that emerged included permanence and visibility of disability, the inability to 'cure' disability, and difficulty being less severe than disability.

[30]A positive response was when a person has a disability.

The focus of the analysis was to identify patterns of differences and similarities in the responses to questions and in the comments made, and to recommend ways in which these patterns could be confirmed or rejected in a follow up national survey undertaken by StatsSA (2006).

The three groups of allocated disability status were analyzed separately – all 'disabled' groups together, all the 'unsure' groups together, and all the 'non-disabled' groups together. The list of codes applied across the three sets of groups were the same. The codes were compared across the three disability status groups.

3.8.2 The Agincourt data

a) In-depth cognitive testing interviews – March 2009

These ten interviews were analyzed for consistency of responses across respondents and patterns of interpretation of questions, as is suggested for cognitive testing interview analyses (Miller & deMaio 2006; Miller & Willson 2009; Willis 2005). The focus of the analyses considered the following:

- The ease of question administration, the need for repetition and explanation of the question, and whether respondents felt these questions were of relevance to their lives.
- The interpretation of the question intent as evidenced from responses to probe questions asked, and the elicited narrative.
- The patterns (if any) of misinterpretations across the ten respondents for the different domain questions. The analysis looked for congruence between the interpretation provided by the respondent and the one intended by the question designers.
- The consistency of interpretations (congruent ones and misinterpretations) in the narrativesacross the ten respondents and within those of individual respondents.

b) Semi-structured interviews – May/June 2008

The data from the 69 interviews were entered into Excel and exported to SPSS (version 17.0) for analysis. A lengthy process of data cleaning and coding was undertaken. This is described in detail to ensure replicability.

i. Coding of open ended responses:

The responses to open-ended questions were reviewed, coded and added to the data set as quantitative codes. For example, respondents were asked if they were satisfied with their lives, and the responses were coded into 1=Satisfied, 2=unsatisfied, and 3=non-committal. These codes were added to the database for the analysis. Similarly, codes for the list of factors listed in Appendix 6a, were included in the Excel data set, together with notes on the comments made by respondents. The coding was based on grading of responses given by respondents and observations during data collection in the five villages.[31] All the codes are based on self-reporting by the respondents. For example, disability status was the response given by the participant, when asked, at the end of the interview, 'Are you disabled?'. As these were semi-structured interviews, the codes reflect the information that was elicited through the questions, and does not include aspects that might have been mentioned in less structured and more in-depth interviews. Since the process of coding was a relatively technical one (as shown in Appendix 6a), it was deemed sufficient to do one round of coding only.

ii. Computing domain scores and total functioning scores

Different approaches can be used to analyze and summarise data on functioning (Murray & Evans 2003; Mont & Loeb 2008; Loeb, Eide& Mont 2008; Mont & Loeb 2010). The approach used in this study is an adaptation of the one described by Mont and Loeb (2008) to create a scale of scores

[31] Observations included the structure of the dwelling, presence of livestock, other people living in the dwelling, etc.

using a simple weighting system. This scaling approach is a simple technique that allows the scores to be analyzed in a comparative manner, where each domain contributes the same weight to the overall score, even if different domains include varying numbers of questions. Other researchers have used more complex methods to scale responses and calculate summary measures of health (for example, see Murray and Evans 2003). However, the aim of this study is to explore the performance of these questions rather than creating summary measures. Hence the simpler approach was used to facilitate analysis.

A scaling process was applied to ensure that any one domain score had the same weight on a scale from 0 to 140, where a higher score reflects worse functioning or more difficulties. The scale of 0 to 140 was used practical reason that there were seven domains and each domain contributed maximum of 20 points to the overall score.

The scale I used has the following characteristics:

- Only the questions from the SAGE questionnaire were used, to allow for testing of the findings from my analysis against the full AHPU Census 2006 data set at a future date.
- There wereseven domains covered by the SAGE questions. The two domains not covered in SAGE are that of communication, which was covered by the use of a single question in the WG Short Set, and hearing. The sensory domain in the SAGE comprises of only a vision question. The WG Short Set did not include the domains of affect, pain and sleep.
- The questions each have five response options (1 – 5) with '1' being 'no difficulties', and '5' being 'extreme difficulty/unable to do'. The sum of the response codes for all the questions in one domain, was used as the total score for that domain. The higher the score for a domain the worse the reported difficulty.
- In order to ensure the same contribution of a score out of 20 by each domain, where the different domains have different numbers of questions, a multiplier factor was applied to

the total score for that domain (sum of question scores).The total score possible for any domain was the number of questions X 5 (response options). This total (5, 10 or 15 in Table A6in Appendix 6b) was then divided into20 – the allocated proportion for the domain. The result gavethe multiplier factor to be applied to each total domain score. For example, for three questions, the total score was 15. The division of 20 by 15 yielded a multiplier factor of 1.33; similarly for two and one questions the multiplier factor was 2 and 4 respectively. Thus, if a person had responded '2', '3',' 2' on each of the three mobility questions respectively, the total domain score for that respondent was 7. The domain score for the scale is therefore 7 x 1.333 (multiplier for 3 questions) = 9.331. This score was then added to the total score for the other six domains for that respondent, to give the final score on a scale 0 - 140.[32]

The seven domains used in the analysis of the SAGE data are sensory, mobility, cognition, self-care, affect, sleep and pain. The WG data includes the additional domain of communication and an additional subdomain, hearing, for the sensory domain. Reponses to the two additional questions (communication and hearing) from the WGShort Set were reviewed, and the responses indicated very few people reporting difficulties. Any influence they may have if they were included in the analysis, would be minimal and would reduce the overall functioning score. I decided that this was sufficient reason to focus on the SAGE questions only.[33] Thus profiles of functioning for the 69 respondents were created by calculating total scores based on seven domains of the SAGE questions. The details of this scoring process are presented in Appendix 6b).

[32] No respondent had a TFS of less than 39 as 'no difficulty' used the code '1'.

[33] If the WG Extended Set had been used for the 69 interviews, a similar procedure would have been applied as that applied to the SAGE questions, as there is a better match of the domains between these two sets than between the SAGE and WG Short Set.

iii. Categorization of the data into functioning profiles

The data were coded into twotypes of profiles or typologies – 1) type of difficulty and 2) severity of difficulty –basedon the responses of the functioning questions and the calculated TFS. These profiles wereanalyzed in relation to the different life context factors coded from the respondents' descriptions of their life context (see coding of the open ended questions described above).

1. Severity and type of difficulty profile.

Severity of difficulty

Severity was coded into five categories based on the total score for each domain:

- no difficulty – TFS = 0 - 39
- mild difficulty – TFS = 40 - 59
- moderate difficulty – TFS = 60 - 79
- severe difficulty – TFS = 60 - 99
- extreme difficulty/cannot do – TFS = 100+

Type of difficulty

The type of difficulty was determined by the domain that contributed the highest score out of 20 to the TFS. This was the domain reported with the most difficulty by a respondent. For example, if pain and fatigue both had the same and highest scores (out of 20), the type of difficulty would be noted as being pain and fatigue (pain/fatigue).

Each respondent was allocated a categorization of both their severity and type of difficulties, and the relevant code added to the database. The data were analyzed using basic frequencies and correlations to determine the relationship between the profiles and respondents' life context factors. No statistical tests were applied.

2. Life context factors

The semi-structured interviews collected information on a range of factors, as described and coded above. These factors were analyzed individually in relation to the severity and type of difficulty profiles. The factors considered are presented in the section above on coding open-ended responses, and included: receipt of a social assistance grant; salary or income available other than a social assistance grant; one or more statements of religious belief; level of activity described (moving around the dwelling only or beyond); assets (e.g. livestock); savings (whether savings are possible or not); social networks (who they interact with – just family or beyond the family); andinvolvement in community events and organizations (e.g. burial societies, church groups).The remaining variables (age, sex, presence of a health condition, disability status, satisfaction) were used asreported without any further coding. Crosstabulations calculated includedthe relationship between the different profiles and level of satisfaction, self identified disability status and/or presence of a health condition, and age.

3.9 Ethical considerations

Ethics clearance was obtained from the University of the Witwatersrand's Human Research Ethics Committee (Medical) prior to the start of the focus groups (Protocol Number: M060125). The certificate is included in Appendix 8. The ethical clearance was given without any conditions attached. All focus group participants were given information on the project before being asked to given written consent. While the focus group participants were given a cash honorarium, none were informed of this prior to their participation, other than that their transport costs would be reimbursed. All participants were given an information sheet with a phone number to call if they should need any support after the group. When asked after the focus groups whether they felt good or bad about the topics discussed, no one expressed any negative feelings, while a number said they had enjoyed being able to discuss these sometimes difficult feelings and thoughts in an open manner.

The data collection procedures in Agincourt were submitted for ethical clearance to the Research Ethics Committee for Human Subjects (Medical) at the University of the Witwatersrand and clearance was given with no conditions attached (Protocol number: M080222). The clearance certificate is attached in Appendix 8. In addition, the project was discussed and authorised by the AHPU staff and an ethics clearance application was submitted to the Department of Health and Social Services of the Mpumalanga Provincial Government.

The information letters were translated into Shangaan by the AHPU staff and a copy given to each respondent. As for the focus group participants, the information on the project was explained to everyone, before inviting them to participate. A phone number was provided on the information sheet, in case a respondent felt distressed from the interview or needed further information.

The consent form was signed by the respondents for the initial interview (May/June 2008), the audio recording of the initial interview and for taking part in the second follow up interview (10 interviews from March 2009), and audio recording of that interview.

The respondents interviewed in March 2009 were provided with a small incentive to thank them for agreeing to provide a further interview. This was only given to them at the end of the interview and was not mentioned until then, and, thus should not have biased their willingness to be interviewed in any way.

When asked at the end of the interview and the focus group discussions if respondents had any questions or were worried by anything that had been discussed, no complaints were made, other than four respondents mentioning concerns about the time taken and the lack of immediate benefit in the improvement of services. More commonly, people reflected on the good feeling they had from discussing and reflecting on the topics of the interview. The consent process included information on the confidentiality of the information, the voluntary nature of the respondents' participation, their ability to withdraw at any point in the process, and that they would not benefit

directly from this research. However, it was explained that the research findings would be beneficial for policy makers.

There were no untoward incidents related to ethics in any of the data collection phases.

3.10 Reflexivity

Reflexivity is an important component of any research and most importantly when doing qualitative research, where reflexivity is integral to the data collection process, as described by Lynch (2000), for example. Lynch states that '[reflexivity] is an unavoidable feature of the way actions (including actions performed, and expressions written, by academic researchers) are performed, made sense of and incorporated into social settings. In this sense of the word, it is impossible to be unreflexive.' Given this statement, Lynch goes on to critically discuss a range of different approaches to reflexivity which vary in the degree to which they are part of the underlying theoretical or methodological approach of the research. He concludes that all approaches to reflexivity 'involve some sort of recursive turning back' and at the basic level, includes reflection on what one's relationship is as a researcher, with the group of people who are the participants in the research. He refers to this latter approach as 'methodological self-consciousness'. I have embodied in my thesis a number of features of 'methodological self-consciousness'. Examples include:

- The analysis of the limitations of trying to do in-depth qualitative work as a white English speaking person, but that knowing some Shangaan allowed me to establish a good rapport with the respondents. I discuss this in the methodology chapter where I describe the change in how I ran the 10 follow up interviews, compared to the initial 69 interviews (Sections 3.7.2 a and b)

- The recruitment of people only with disclosed HIV status for the HIVAIDS focus groups, to avoid the group disclosing someone's status inadvertently after the group discussion.

- The use of a method (cognitive testing of survey questions) to go beyond my own assumptions about how questions are interpreted, and to find the voices of the respondents.

My selection of the AHPU as my base for doing the 69 and 10 follow up interviews, was a reflection of my awareness of what it means to go into an area where one is 'foreign' to do interviews. The 'readymade' infrastructure offered by the AHPU allowed me to contextualise myself and my research for the participants, who are used to being part of research conducted by the AHPU. I reflect on this in Chapter 3 (Section 3.7.2) and in the limitations of the study in Chapter 8 (Section 8.2). My 'foreigness' was further attenuated by my knowledge, albeit limited, of Shangaan and of the area because of having grown up in that part of South Africa.

Chapter 4

The difference a word makes – 'disability' and 'difficulty'.

This chapter presents the results on the effect of question wording, comparing three questions that asked about 'difficulty' or 'disability/disabled' (red card at the back of thesis):

a) WG Short Set (Difficulty in seeing, hearing, walking and climbing stairs, remembering and concentrating, self-care, and communication) (see red card)
b) the 2001 South African Census question on disability ('Do you have any serious disability that prevents your full participation in life activities (such as education, work, social life)? – none, sight, hearing, communication, physical, intellectual, emotional)
c) 'Are you disabled?'

The structure of the chapter flows from these three questions. I start by comparing the responses to these three questions of the 185 adult participants of the 21 focus group. I then look in more detail at the three sets of focus groups ('disabled', 'unsure' and 'non-disabled') to see whether an *a priori* allocation of disability status is replicated in the differences in responses. This leads me to discuss what these results indicate about the effectiveness of the WG Short Set. The chapter concludes with a review of how the focus group participants and Agincourt respondents understood disability.

The specific research questions to be addressed in this chapter are: a) How many people report a difficultyor disability on the three sets of questions?; b)What are the major differences between people who are 'disabled', 'non-disabled' and 'unsure' (allocated disability status) in how they respond to the three sets of questions – WG Short Set, 2001 Census Question and 'Are you disabled'?; c) How do people's description of what disability is fit with their understanding of and attitudes on disability?

The data used for this analysis included the structured questionnaires administered to respondents prior to the focus groups, the comments made by the focus group participants on the meaning of 'disability' and 'difficulty', comments made by the 69 interviewees on their own reported disability status, and further discussion of their understanding of disability.

Because of the many different references of the term disabled (or disability), I use the term 'disabled' with inverted commas, to refer to the status of the person when counted in the statistics for each measure or to the *a priori* disability status I allocated to the different focus groups. The use of the term disabled without inverted commas, refers to self-identified status or a general use of the term.

4.1 Comparison of responses to three disability questions

The responses on the focus group questionnaire are presented first. (See also Schneider 2009). As described in the analysis section of the previous chapter, the responses were coded into two different levels of severity, as proposed by the WG in the analysis of the Short Set (Washington Group 2005): D1 included all people who had responses indicating 'some difficulty', 'a lot of difficulty' or 'unable to do' for one or more of the questions;D2 included all respondents who indicated having 'a lot of difficulty' or 'unable to do' for one or more of the questions; and D3 included only people who reported 'being unable to do' for one or more of the questions. An initial analysis showed that the D2 results were consistently in between D1 and D3, and are not presented here.

The results are presented for each of the three allocated disability status groups ('disabled', 'unsure', 'non-disabled') and similarities and differences highlighted. The results on the quantitative questionnaire are presented as simple frequencies. In total, 185 adults took part in the focus groups and the demographics for this group are presented in Table 4.

The adult sample showed a wide range of ages, as expected from the stratification applied. The majority were women and the education levels varied, with the majority having only primary or some high school education. Just over half of the participants were employed. The majority had never married, a fact that reflects a high number of young and/or disabled people, who are often not married due to social stigma.

Table 4: Demographic descriptors (in %) for the 185 focus group participants by disability status**

Variables	'Disabled' (N=75)		'Unsure' (N=54)		'Non-disabled' (N=56)	
	N	%	N	%	N	%
Sex						
• Male	40	53	12	22	20	36
• Female	32	43	41	75	36	64
Age						
• <=30 yrs	29	39	17	31	33	60
• 31 – 60 yrs	45	60	29	53	21	38
• 61+ yrs	1	2	9	16	2	4
Education Level						
• No schooling	3	5	6	11	1	2
• Primary school	11	15	14	26	12	22
• High School	44	58	31	57	21	38
• Post school	16	21	2	4	20	36
• Don't know/other	1	2	1	2	1	2
Employment status (employed last 7 days)						
• No	35	47	16	29	17	30
• yes	40	53	38	71	39	70
Marital status						
• Never married	25	34	18	33	20	35
• Married/cohabiting	42	56	23	43	31	56
• Widower/widow/ divorced/ separated	8	10	13	24	5	9
Living context						
• Independent	46	61	33	62	47	84
• With personal attendant	20	26	15	27	6	11
• Institution/hospital	7	10	3	6	1	2
Total for each variable		**100**		**100**		**100**

** The selection of participants was entirely purposive and, therefore, the percentages presented in the table are a reflection of this and are not representative of the general population of 'disabled', 'unsure' and 'non-disabled'. The percentages are rounded and missing data are not included.

Figure 5 presents the comparison between the three sets of questions on disability – the WG Short Set, the South African Census 2001 question, and the question 'Are you disabled?'.

The results for the Census 2001 and 'Are you disabled?' were similar, suggesting that both questions counted people who self-identified as disabled. However, the respondents answering these two questions were not always the same. Some physically impaired and blind respondents responded 'no' to the Census 2001 question, but 'yes' to 'Are you disabled?' The reason they gave was a reaction to and response focussed on the introductory phrase of the question, which asked about being prevented from participating in everyday life. They said, quite categorically, that they were participating in everyday life. These physically disabled and blind respondents were, therefore, not counted as 'disabled'.

'Unsure' respondents were clear about not being disabled ('no' for 'Are you disabled?') but some seemed comfortable responding 'yes' to the Census 2001 question. This may be because of the various impairments listed in the second part of the question.

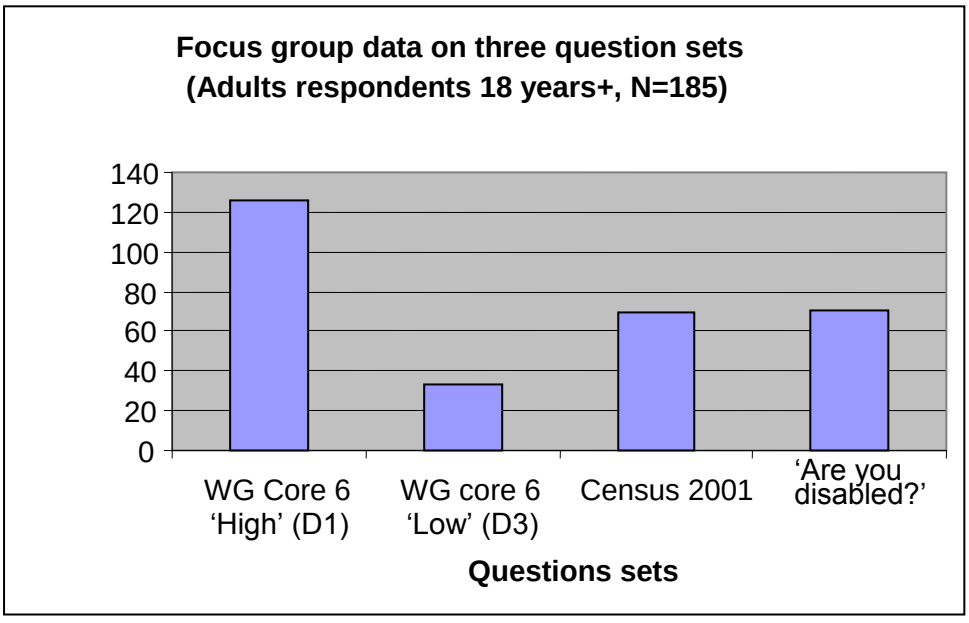


Figure 5: Comparison of responses given by 185 focus group participants for Census 2001 questions, WG Short Set composite score and 'Are you disabled?'

The WG D3 estimate ('unable to do') generated the lowest number of 'disabled' people in the sample, suggesting that this question identified people only with significant difficulties in functioning. People who see themselves or are seen by others as disabled, did not necessarily have the most severe difficulties ('unable to do'). This is shown by the estimates for the other two questions being higher than those for D3 – i.e. fewer people reported being 'unable to do' one or more activities than reported that they were disabled. Reporting 'yes' to having a 'serious disability' is not consistently related to having severe difficulty in doing various activities, or severe functional limitations.

The WG D1 estimate reflects the inclusion of a high proportion of people with mild difficulties, who responded as having 'some difficulty' and were counted as 'disabled'. These people did not see themselves as being disabled, but were willing to report some difficulty in functioning in one or more of the domains included in the WG Short Set questions. Their 'some difficulty' is useful information to ensure that services are provided to prevent these difficulties becoming 'a lot of difficulty', and as a baseline measures of functioning for comparison with later measures, for example, in a population based survey.

In the results presented in Figure 5, a respondent was categorized as 'disabled' if he or she had responses that met the following criteria:

- Reported any difficulties on the WG Short Set
- Responded 'yes' on the Census 2001 question
- Responded 'yes' to 'Are you disabled?'

4.2 Allocated disability status and responses to the three questions

As described in Chapter 3, each of the 21 adult groups was allocated one of three disability status categories: 'disabled', 'unsure' or'non-disabled'. Figure6 presents the estimates for each question for these three status categories. The results show some important trends.

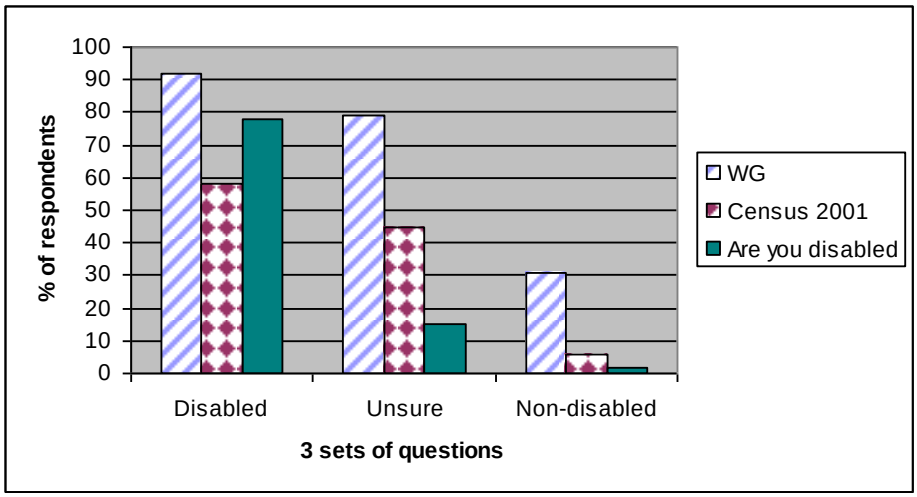


Figure6: Percentage of participants in each allocated disability status category identified as 'disabled' on each of three question sets

The majority of 'disabled' group participants were counted as 'disabled' by the WGShort Set (91%) and 'Are you disabled?' (78%). In contrast, only 58% of participantsfrom this group responded 'yes' to the Census 2001 question. Just under 80% of the 'unsure' group participants were counted as 'disabled' by the WG questions (i.e. reported having difficulties) but fewer (just over 40%) were counted as 'disabled' by the Census 2001 questions. The 'Are you disabled?' question identified very few participants (15%) from the'unsure' groups as 'disabled'. Few participants (30%) from the 'non-disabled' groups indicated having any difficulty in response to the WG questions, but none responded as being disabled ('Are you disabled?") or 'yes' to the Census 2001 questions.

Figure 7 presents a further breakdown of the group response patterns for a selected number of illustrative groups. The *apriori* allocated disability status was: 'disabled' for the 'vision disabled' and 'schizophrenia' groups; 'unsure' for the 'HIV/AIDS', 'chronic illness' and 'elderly' groups; and 'non-disabled' for the remainder of the groups.

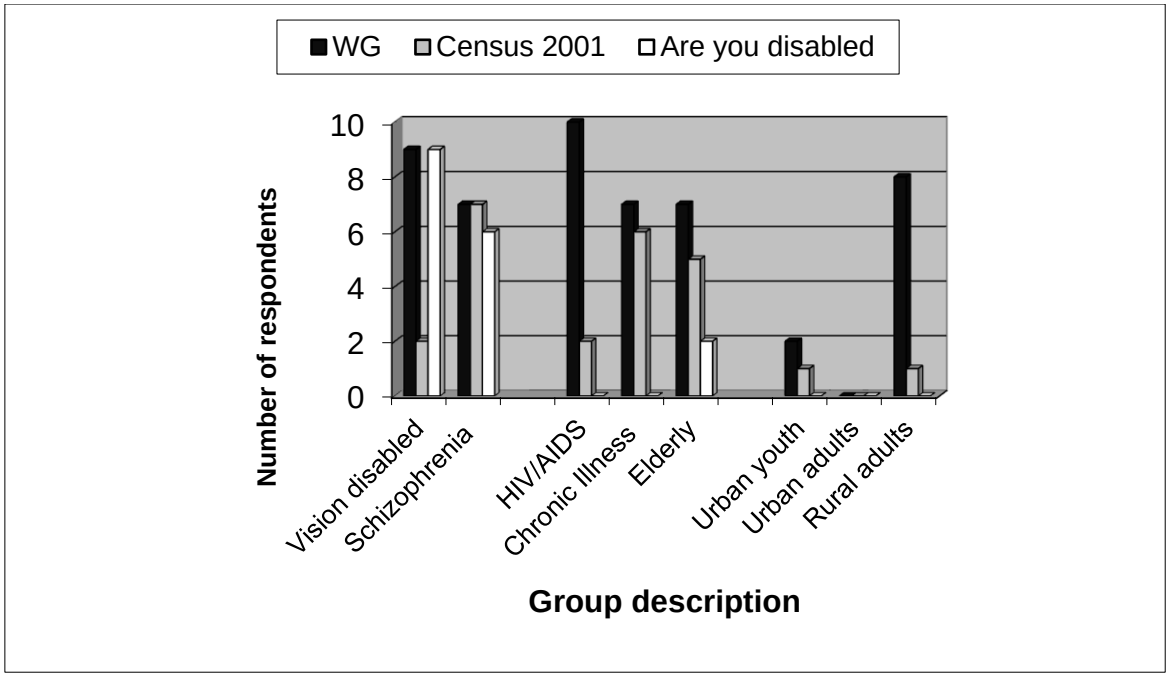


Figure7: Number of adult participants counted as disabled on the three question sets for a selection of individual groups

The physically and vision disabled groups were much less likely to respond as 'disabled' to the Census 2001 questions, compared to their responses to the WG Short Set and 'Are you disabled?' questions. This suggests that the two 'disability' questions were more likely tomeasurean identity status, than level of functioning. A number of participants (notably in the groups of blind and physically disabled people) responded 'no' to the Census 2001 question. When this response was queried in the focus group discussion, they explained that theydid participate in life activities (as asked in the introductory phrase) and hence responded with 'none'. The same participants responded 'yes' to 'Are you disabled?', reflecting their sense of identity as a disabled person. They further explained that they experienced difficulties in some domains of functioning because of their specific impairment, but despite these, they were able to do most of what they would like to do.

The trend among participants of the 'unsure' group was a consistent reporting of difficulties (WG Short Set), varied responses on the Census 2001 questions, and strongly rejected the notion of being 'disabled'. In focus group discussions, participants acknowledged having difficulties but emphasised that they were not disabled:

> I am not disabled but there are times when this pain is so severe that I can hardly wash myself. But I am not disabled. [rural, HIV/AIDS group]

Youth and adults in the 'non-disabled' group were generally clear that they did not have any difficulties and were not 'disabled'. The two exceptions were some 'non-disabled' participants in rural groups who indicated 'some difficulties', whilemaintaining the position of 'no serious disability affecting their participation in daily activities' and 'not being disabled'. This is a consistent response, if the two 'disability' questions are assumed to identify more severe difficulties or disability. This latter 'non-disabled' groups did not have severe difficulties.

4.3The effectiveness of the WG Short Set

Quantitative analysis show that the WG D1 estimate identified many more people as having difficulties than either the Census 2001 or 'Are you disabled?' question. The next step is to understand whether this is accurate or an over identification of the number of people, who have difficulties or who would be counted as 'disabled'. A criticism of these measures can be that they are over-inclusive and not sufficiently discerning to be useful. One can argue that if too many people are counted in, the whole purpose of addressing the needs of severely disabled people may be lost.

This criticism appears warranted given the information from the focus group responses. However, further interrogation of the responses obtained on the WG Short Set shows that this is not entirely the case – it depends on the cutoff point that is applied for counting a person as 'disabled'. The data,in themselves, areinsufficient to determine the prevalence estimate. A political or administrative decision is required to decide where the cutoff should be placed. For example, in determining who should be eligible for disability-related benefits, respondents reporting only 'some difficulty' should not be counted as 'disabled'; but when planning and estimating the cost benefitsof an accessible transport system, all people who report any, even 'some difficulty' in walking and climbing stairs,should be counted 'disabled'. This would be an accurate reflection of the population

who would derive benefit from such a transport system.[34]The decision on where to place the cutoff point, or, in other words, what definition of disability to apply, is largely a factor of political will and financial and human resources available.

A national population based survey, using a representative sample of 6000 households, was carried out by Statistics South Africa (the government statistical office) to further test the proposed questions for Census 2011(StatsSA 2006; Schneider, Dasappa, Khan & Khan 2009). The results of the survey replicated the responses from the focus group participants. The WG Short Set provided higher estimates of prevalence of disability in the population than did the Census 2001 question. Of the population 15 years and older, 2.5% reported 'unable to do' at least on one activity, 9.9% reported 'a lot of difficulty' on at least one activity, and a further 20% reported 'some difficulty' on at least one activity. These are weighted estimates for the population 15 years and older.

The vagueness of the Census 2001 question, which used the phrase 'serious disability,' is highlighted by the fact that 23% of respondents, who only reported 'some difficulty' on one or more activities (WG Short Set), responded 'yes' to the Census 2001 question (StatsSA 2006). These could be explained asbeing, firstly, an identity status response to the census 2001 question; secondly, a reflection of the presence of facilitators in the environment, thus, reducing the impact of activity limitations;[35]or, thirdly, an underestimation of their difficulty as reported on the WG Short Set. Whatever the explanation, the phrase 'serious disability' (which presumably should only identify 'a lot of difficulty' and 'unable to do' responses), in fact also identifies mild difficulty. The findings of the WG/UNESCAP cognitive interview and field testing of the WG Short and Extended Sets (UNESCAP

[34] The point can be made that there is no need for a survey to determine how many people need accessible transport. All built environments should adhere to a basic generic level of accessibility for all impairment types. However, statistics are useful to generate the political will to create the generic level of accessibility.

[35] It is not clear whether respondents do or do not include the impact of these factors in giving their responses to any of the questions except for the seeing and hearing questions on the WG Short Set which specify with use of eye glasses or a hearing aid respectively.

2010) suggests that people report ‘some difficulty’ when these are, as described in the narratives, minor andmore like everyday niggles, that may cause them some concern but not much. However, the 23% of respondents who had only ‘some difficulty’ also reported ‘yes, seriously disabled’ on the Census 2001 question, suggesting that, while these may reflect ‘mild niggles’, they nevertheless are significant enough to elicit an identity of being ‘disabled’. The Census 2001 question, it seems, fails to provide transparent information on severity, and the statistics generated by this question are difficult to interpret for policy and programmepurposes.

The WG Short Set used four response options (‘no difficulty’, ‘some difficulty’, ‘a lot of difficulty’ and ‘unable to do’) compared to the ‘yes/no’ response options provided for the other two questions. The high rate of responses indicating ‘some difficulty’ (reflected in the difference between WG D1 and D3) suggests that people are comfortable reporting ‘some difficulty’, if given the option, but remain reluctant to commit themselves to a ‘yes’ when this is the only alternative to ‘no’. The use of ‘yes/no’ response options for the two ‘disability’ questions, suggests the need for further research to determine the effect of a different number of response options. For example, what would the difference in responses be to using yes/no versus four response options when asking about ‘difficulty’ for both?

In conclusion, the results from the focus group data, substantiated by the survey findings (StatsSA 2006), suggest that the WG Short Set provides a more accurate and transparent measure of severity of difficulty than the Census 2001 question. The Census 2001 does not provide a clear indication of severity on its own, supporting the explanation that it is measuring an identity statusrather than functional status. The survey did not compare the three sets of questions, as was done in the focus group data, and, thus, it is not possible to say how the ‘Are you disabled?’ question would compare to the Census 2001 question, in the response patterns for the whole population of people 15 years and older.

The WG (D3) gave a lower estimate of disability than either the Census 2001 or the 'Are you disabled?' question. This suggests that the D3 measure only identifies people with very severe difficulties, while the Census 2001 and 'Are you disabled?' questions identified people with less severe difficultiesas also 'disabled', as shown from the survey data above.

The WG Short Set is, therefore, more inclusive and provides a more pragmatic and descriptive, andsimpler way of counting people, who experience a greater or lesser degree of disability. It is a more effective measure of functional status. The criticism that it is too inclusive can be countered by the argument that it depends on where the cutoff point is situated – adecision dependent on political will, administrative requirements and available resources. The use of different cutoff points gives rise to different statistical estimates. Any estimate of disability must be understood in relation to the measures used and the cutoff definition applied to the data. There is no single disability estimate.

The WG Short Set questions were seen as being 'good' questions, 'easy to answer' and 'not too long to remember'. Participants in one 'non-disabled' group expressed emphatically that, since the questions were about 'disabled' people and they were 'normal,' they had to say 'no' to all the questions. The focus group study was introduced as being about testing questions on disability, which led to this statement. Few problems were noted with the questions themselves and they were seen as reflecting people's lives, as indicated by a remark from two participants:

> And what I liked a lot about these questions is that there are things that happen in our daily lives of which we aren't willing to discuss them with people around us, because they might look down on us but here [in answering the questions], we get a chance to voice those things. [rural, elderly Zulu group]

> These are the kind of questions which… I don't know how you are going to do this, but this must be elevated. These people [referring to those using the statistics] must see how we

are, how we feel as physically challenged and disabled. They must know about us. [urban, head injury group].

4.4 Understanding disability

I set out how disability is understood and defined in Chapter 2. However, this understanding is not necessarily the same as that of people not disabled and not involved in any disability related field of work. Their understanding offers a lens on explaining why disability remains a highly stigmatized phenomenon. The majority of focus group participants and all the Agincourt respondents were from lower socio-economic and educational backgrounds.

4.4.1 Focus group participants

Participants in all groups regarded disability as a permanent feature of an individual, it renders a person dependent on others as they are unable to do 'anything' for themselves, and it is predominantly a physical and visible attribute of an individual. In addition, a condition that defines disability is not 'solvable' nor 'curable,' nor 'can it be changed'. There was a strong notion of 'them' and 'us' expressed by the 'non-disabled' and 'unsure' participants, and even by some of the 'disabled' participants about people with impairments different to theirs:

> What is the meaning of disabled? Why do you say that blind people are disabled or people in wheelchairs are disabled? Just because they can't use their legs, disabled in that sense they can't walk, but they can, they are able to do many things, whatever… It depends on what, in what situation you are. [urban, vision disabled group]

> Very often, able bodied people do not want disabled people to participate in activities with them. They regard disabled people simply as people who want to interfere in their affairs. [rural, psychiatric group]

Similar views were expressed by participants in the 'non-disabled' groups:

> When I think of disabilities, I always think of people in wheelchairs or blind. I do not actually think of those people who cannot see at a distance or with emotional or social problems. [urban, youth, non-disabled group]

> According to me, having a disability is not having the use of all of one's limbs. It's a visible disability, as in the case of having lost an arm, an eye, or your hearing. That is how I see someone who is disabled.[rural, non-disabled group]

The 'unsure' groups also gave clear descriptions of a disabled person being someone 'who is not able to do things for themselves and (is) always sleeping', 'without hands or eyes', 'with no legs'. One participant with a chronic illness made it clear that she was not disabled:

> Participant: …disabled is when you can't do nothing [anything].
> Moderator: So do you see yourself as being disabled or not?
> Participant: No, I don't think so because I can still walk and I can still see. [rural, chronic illness group]

This understanding of disability suggests strong negative connotations with the term 'disability.' People recognise the stigmatising nature of disability. These negative connotations discourage self-identification as disabled, even by people with significant functional limitations. The quantitative results bear this out as the number of respondents counted as 'disabled' was much higher for the WG Short Set (D1) which used the term 'difficulty' instead of 'disability' (see figures5 - 7 above).

Disability is seen as permanent, and without solution or resolution:

> To have a difficulty is something which I'm faced with, like not having things you would like to have. For difficulties, one can change or can have a solution, unlike disability, there is no solution there. [rural, vision impaired group]

> A disabled person is someone who is always in the wheelchair and cannot do anything for him or herself. They rely on family members for help. This we call a disability. Then a person with difficulty is a person who has stress from different illnesses, for example, heart problems. So when they have to do things they face difficulties. So this person is having a difficulty - not disabled. [urban, chronic illness group].

The participants in the Deaf group, in particular, raised the economic value of using the label 'disabled' for specific purposes, such as when applying for social assistance benefits, but did not, necessarily, want to adopt the label as an identity:

> I think that I would like to support the word disability and that I am disabled, because I then have lots more access [to support] if I say that I'm disabled. [urban, Deaf group].

4.4.2 Agincourt respondents

The 69 respondents from Agincourt were asked 'Are you disabled?' at the end of the semi-structured interview. Of these participants, 14 said they were disabled, 54 said they were not disabled, and one had a missing response. The explanations given by the respondents are analyzed thematically, and reflect similar themes to those identified by the focus group participants. The majority of respondents who reported difficulties did not identify themselves as disabled.

a) Inability to do anything

As for the focus groups, the interview participants were quite clear on what disability entails – disabled people are unable to do anything for themselves and need to be cared for. Of the 69 interviewees who made a comment, 38 indicated that a disabled person is unable to do things. People who self-reported being disabled explained that they were not able to do the things they wanted to. These comments situate disability strongly within the realm of functioning.

A disabled person is seen as someone who, for example, 'cannot do things properly on his own' or 'is unable to do things and unable to think carefully like I do'. The respondents described different

types of impairments of a physical, sensory and mental nature. A respondent who reported being 'not disabled' said: 'My legs, hands and mind are functioning well. I'm able to do everything I want but a disabled person can't do things', while another respondent said disabled people were 'deaf, blind, dumb and wheelchair users'. Those respondents who reported being 'disabled' described themselves as having difficulties doing things: 'I'm unable to do my different activities as I wish' or 'I cannot stand or walk'.

One respondent raised the notion of being 'better' than a disabled person: 'I'm far better than a disabled person. I've got eyes to see, hands to work and legs to walk; I'm just facing the hardships of this world.' The last part of this comment resonates strongly with the analysis in chapters 5 and 6, where respondents report minimal difficulties on the traditional domains of disability, including seeing, hearing, mobility, communication and self care, but report problems with anxiety, depression, pain, and sleep/fatigue. This particular respondent reported quite high levels of difficulty with affect (anxiety and depression), sleep and pain on the SAGE questions analyzed in Chapter 6, and no difficulty on the traditional domains of disability.

b) Loss and religion as part of disability

The word for disability in Shangaan is '*tsoniwa*' and for difficulty '*tikeriwa*'. When discussing with Shangaan speakers the connotations of the word '*tsoniwa*', the notion of a loss as part of what being disabled means, was mentioned by a number of respondents. Being an orphan or not having a family who loves them were examples of loss that is seen as disabling. Some of the participants referred to being an orphan, but also added that a disabled person had various impairments: 'Adisabled person is someone who is an orphan, who lost his/her parents; I'm disabled because I lost all my parents'; 'I lost my parents [and therefore am disabled]' and the same respondent continues with: 'A disabled person is unable to do anything - a crippled one'. These references to loss raise an interesting point about stigmatization. If people are stigmatized because of disability, the question is whether they are stigmatized in a similar way if their *tsoniwa* is due to a loss of family rather than loss of function.

The narratives from the respondents did not include discussions on these different types of loss to allow me to comment further on this.

People who reported being 'not disabled' also juxtaposed the two types of loss in their definitions of disability, and stated that they had neither type and, hence, were not disabled: 'I have a wife. A disabled person is a person who cannot see, has no hands and also using a wheelchair' or 'A disabled person is person who does not have a family, cannot walk, see or do manual work. I've got a family - I'm not disabled'. Two respondents referred to the family loss only, and not the functional loss, but added the reference to being a churchgoer as a reason for not being disabled: 'I'm not disabled because I'm a Christian. A disabled person is someone who lost his parents' and 'I go to church I have God. A disabled person is someone who does not go to church, who has lost [his or her] parents, and is an orphan'.

The importance of religion is noted in the latter quotes, but were not evident in any comments made by people who reported being 'disabled'. The notion of 'healthworlds', put forward by Cochrane & Germond, (2010) explains the unity of body, mind and spirituality as a marker of wellbeing. If this unity has been lost it could be identified as disability, in the sense of a loss. This loss of unity could also explain one respondent's comment that a disabled persons is'onewho walks with a wheelchair, does not have hands or fingers, or his mind. He is not a true Tsonga.'[36] A description of the history of the Shangaan/Tsonga people in the Bushbuckridge region, where Agincourt is located, shows the different conflicts that have arisen between the Tsonga and other tribes in the area, such as the Sotho people (Niehaus 2002). The conflicts were as much about territory and land, as about identity. The loss of this identity may also be part of the loss of disability.

[36] The terms Tsonga and Shangaan are used interchangeable as they refer to the same linguistic and ethnic group of people.

c) Difficulties are part of normal life

A number of respondents spoke about their difficulties (not disability) being part of normal life and the ageing process, as explained by one respondent: 'No, I was born being fine [i.e. able to do everything and with no impairments] - it happened as life goes on'.

The analysis shows that respondents have clear notions of what disability means, and they apply these in their responses to the question 'Are you disabled?'. The main aim of my thesis is to show that the wording has an effect on responses, and not to analyze the meaning of disability. But this brief foray into the realm of meanings of disability provides interesting evidence of many different themes that underlie these meanings.

4.5Implications of findings on the effect of wording

The results presented in this chapter highlight two major findings. The first is the difference between measuring an identity status and measuring functional status, and the complex layers of meanings attributed to the term *tsoniwa* in Shangaan, particularly. The second, related but more technical finding, is the importance of asking about 'difficulty' rather than 'disability', and using a scale of response options rather than a dichotomous 'yes/no' response.

The use of the word 'disabled' or 'disability' in a question generally elicits an identity-related status response, without a clear indication of the level of severity. Asking about difficulties provides a more transparent measure of functional status.Measuring identity is important but not a sufficient measure of disability. The 'disabled' identity is generally linked to experiences of disadvantage, discrimination and stigma, and this stigma goes back along time in history and across different religions and culture, as eloquently described by, for example, Baynton (2001), Garland-Thomson (1997) and Miles (1995). This long history, according to Miles (1995), is an indication of the deep entrenchment of this stigma, and the need to distance oneself from such a stigmatized identity.

Baynton (2001) writes about disability as a justification for inequalities in American history, and concludes that disability was central, for example, to all arguments in favour of slavery of African Americans who were perceived as 'defective', the subjugation of women because of 'their physical, intellectual and psychological flaws' noted as 'frailty, irrationality, and emotional excesses' (Baynton, 2001: 41), and, of course, relegation of disabled people to a lower status in society, through 'contempt and pity'. Baynton concludes his essay by saying that 'disability is everywhere in history, once you begin looking for it, but conspicuously absent in the histories we write' (2001: 52). These writings underpin the meanings given to disability in the narratives from my respondents, underscoring the universality of the stigma associated with disability as described by Baynton (2001), Garland-Thomson (1997) and Miles (1995) in a range of different areas of the world.

The stigmatized notion of disability is closely linked to the notion of personhood, as described by Ikäheimo (2009) and reflected in comments about 'us' and 'them' made by focus group participants. Those respondents in the 'disabled' focus groups, who responded 'yes' to the two questions with 'disability' wording, referred to themselves as 'us' (people with disabilities) versus 'them' (non-disabled people). Similarly the people allocated to the 'unsure' and 'non-disabled' focus groups and who do not identify as being disabled, also referred to themselves as 'us' (non-disabled people) versus 'them' (people with disabilities). Furthermore, a disabled person was described by the 'unsure' and 'non-disabled' participants as being someone who cannot do anything for themselves and needing help or, in Ikäheimo's terms, lacking in personhood, by virtue of not contributing and not worthy of contributive valuing. The person is, therefore, not worthy of being included in the 'we' of 'normal' or 'non-disabled people'. I revisit this theme in Chapter 7.

The role of an identity marker is to monitor changes for the group of people so identified, such as increased access to employment, education and social inclusion. However, measures,such as the Census 2001 questions,will reflect a holistic experience of a person, without any clear reference to what aspects are causing the lack of access to opportunities, for example. Measures of identity are

categorical in nature – the person is allocated to a category and much of the person's abilities and disabilities are assumed from there. These measures are, therefore, not good measures of identity either. The question 'Are you disabled?' provided a clear differentiation between the 'disabled' and 'unsure' focus group participants, and may prove to be a good question to add,as an identity status measure, to functional status measures, to describe a person's overall experience of disability.

Measuring functional status provides information that augments and enhances the description of people's experiences. Information is obtained on the degree of severity and response profiles of a person's activity limitationsacross different domains. A range of analyses, using different cutoff points, such as D1 and D3 described above, can be used to determine, for example, the domains of difficulty or degree of difficulty that 'pushes' a person into an identity asdisabled. The measures of functional status include not only all people who identify as disabled, but also many more people who experience difficulties. The service, policy and accommodation needs of the latter are as important as those of the former. The WG Short Set questions are a better option for measuring functional status, than questions that include a reference to disability. The measurement of identity status should be achieved with a separate measure. The investigation of the cutoff point that starts off a process of stigmatization, or the type of functional profile that would generate a reaction of 'us' and 'them', is possible using the combination of functional measures and a measure of identity marker.

4.6 Conclusion

I can now provide answers for the specific questions asked at the start of this chapter. Firstly, question wording does have an effect on the responses people give to questions on disability. If the term 'difficulty' is used, more people report difficulties. In addition, all people who say they are disabled, also report difficulties. The WG Short Set (and similar questions), thus, provide a more inclusive and transparent measure for identifying disability. While this finding is not new, I have not been able to find clear documentation, as noted in Chapter 2, on the size of the effect of differences

between asking about ‘disability’ and ‘difficulty’. The fact that countries like Canada, USA and Australia, ask questions predominantly about ‘difficulty’ suggests that they have found differences, and my thesis provides further evidence of how this difference affects the statistics and in a developing country.

Secondly, the people who respond positively, and are counted as ‘disabled’, on all three questions, are those people who identify as disabled. Those who report difficulties only on the WG Short Set do not identify as disabled. Thirdly, the major differences between different groups of people (‘disabled’, ‘unsure’ and ‘non-disabled’) are, predominantly, between ‘disabled’ and ‘unsure’ groups of people. These differ in their identity status as disabled. The ‘disabled’ groups all responded positively to the WG Short Set, Census 2001 questions and ‘Are you disabled?’, while the ‘unsure’ group were less likely to respond ‘yes’ to the Census 2001 questions and ‘Are you disabled?’, but were highly likely to report difficulties on the WG Short Set.

Lastly, people, who see disability as being unable to do anything and as a mostly physical condition, are consistent in applying this understanding to their responses. Those respondents who felt they were unable to do anything, because of blindness, for example, were likely to say ‘yes’ to ‘Are you disabled?’, whereas those, who had difficulties but able to be independent, said ‘no’ to the same question. The meaning attached to the word ‘disabled’ as ‘unable to do anything’ determined the responses given.

Having shown the benefits of using the WG Short Set, I now turn, in Chapter 5, to considering whether these questions perform as intended by the question developers.

Chapter 5

Interpreting and understanding the question

This chapter applies the Cognitive Assessment of Survey Methodology approach (CASM)(Willis 2005) to evaluate ten respondents' understanding and interpretation of the WG Extended Set of questions. In Chapter 1, I described the CASM approachfor question evaluation. The approach underscores, as Miller and Willson (2009) describe, the role of respondents as informants about their lives, but where these informants do not have knowledge on the underlying reasons for asking the question or question intent. They can, as a result, understand and interpret the question quite differently to its intended meaning (Miller et al.2010). The aim of cognitive assessment of survey questions (or question evaluation) is to document these different understandings and interpretations. A good question, according to Miller and Willson (2009), is one that is relevant not only for answering the research question, but also relevant to experiences of targeted respondents. If the question is relevant to respondents' lives and reality, it will be easier for respondents to make sense of the question and map their experiences onto the given set of response options. In the process of developing good questions, cognitive assessment or question evaluation draws our attention not only to what is wrong with the question, as reflected in incorrect interpretations, but also to identify the potential range of non-problematic interpretations. This information is crucial for a correct analysis and interpretation of survey data (Miller et al. 2010).

The second objective of this thesis is to undertake an evaluation, or cognitive testing, of the questions used to measure disability. In this chapter,I analyze the nature of respondents' interpretation and understanding of the Washington Group's Extended Set of disability questions (WG Extended Set). (These questions are presented on the green card at the back of this thesis.) In this chapter, I investigate: a) whether the questions are understood and interpreted by the respondents as intended by the question developers; and b) the patterns of misinterpretations or

misunderstandings that highlight potential sources of respondent error in survey data generated by these questions. Understanding the performance of questions allows for an informed use of the data rather than making assumptions about what is being measured.

The structure of the chapter is similar for the ten functioning domains comprising the WG Extended Set. For each domain, I specify the question focused on in the evaluation (the first question), and report how many of the respondents had difficulty, and interpreted the question intent correctly or incorrectly. I then present an analysis of the themes arising from the question evaluation for that domain based on the narratives provided by the respondents. The themes include the misinterpretations and the different possible interpretations that nevertheless fall within the scope of the question intent. I use quotes from the respondents' narratives to illustrate these different themes. I follow the analysis of the ten domains with two case studies. The first is that of Respondent 3, an elderly woman, who struggled to provide responses from the given set of options, but interpreted the questions correctly. The second case study is that of a middle-aged man who both interpreted the questions correctly and was able to use the response options effectively. The chapter ends with a review of some major themes that cut across the different domains.

The question evaluation analysis is based on the ten in-depth cognitive testing interviews carried out in March 2009 in Agincourt. These were conducted as cognitive testing interviews, as described in Chapter 3.The WG Extended Set comprises: a) the six WG Short Set questions; b) additional questions for each of the Short Set domains (e.g. separate questions for far and near vision; hearing in noise and hearing in quiet; walking different distances; separate questions for remembering and concentrating); and c) a number of questions for each of four additional domains - affect (anxiety and depression), upper body mobility, pain and fatigue. The analysis is focused on the first question for each domain with additional comments made about some of the extended questions where patterns of responses require this. I focus on the first question as this is the question that will usually determine whether further questions are asked or not, as set out in skip patterns for the questions.

For example, if a respondent says he or she has 'no frequent pain', the questions on the intensity of the pain will not be asked.

In the analysis I focus on: a) the extent to which the response given by a respondent fits the explanations of and examples considered in formulating that response; b) whether the respondent understood and interpreted the question correctly as intended by the question developers; and, c) the extent to which the question is understood and interpreted correctly by the ten respondents. I can comment, from this analysis, on the performance of the WG Extended Set questions, and describe the main patterns of potential misinterpretations to consider when analysing survey data obtained with these questions. This question evaluation process contributes to establishing the validity of the questions.

I use the term 'misinterpretations' (or incorrect interpretation and understanding) with caution. The WG disability questions are phrased for a particular purpose – to get information on the level of functioning, or functional status of respondents. Each question has a narrow intent related to that domain of functioning. The range of potentially correct interpretations are determined by a number of social factors (Miller and Willson 2009), which are discussed in part in the analysis for this chapter, and are the main focus of the next chapter.

In Table 5, I present a summary of the intended meanings of the first questions with their corresponding response options. These intended meanings are compared to the meanings given by the respondents to the same questions in the analysis. The aim of the questions is to obtain a self-report and not a formally and objectively assessed level of functioning, but the extent to which the subjective response approximates an approximate level of functioning is assessed in part by my observations during the interviews, and the examples provided by the respondents. This does not replace an objective measures, for example of vision by an optometrist.

Appendix 5 provides the narratives of all ten respondents for two domains (mobility and anxiety) to give more detailed information on the process of analysis. A table summarising the demographics for the ten respondents is also provided in Appendix 5.

5.1 Vision

The question asked for the vision domain was 'Do you have difficulty seeing even when wearing glasses?'.

All respondents understood the question as being about vision difficulties. All ten respondents gave explanations and examples of using their vision and the difficulties they experienced, if any. Examples included reading generally, differences in reading small and large print, reading in poor light, recognising someone at a distance, or measuring glass for a window as noted by one respondent who was a builder. The level of difficulty reported corresponded to the explanations given for all respondents. This is not necessarily the same level of vision that would be ascertained through a formal assessment by an optometrist.

5.1.1. Understanding the intent of the vision question

Respondent 1 (female, 55 years) answered: 'I have no difficulty when wearing glasses, but when I don't have them, I have difficulty because I cannot see properly.' Respondent 2 (male, 65 years) answered: 'It's a lot of difficulty because my eyes can no longer see when I … like what you've written, I can't see.' Respondent 5 (male, 70 years) answered: 'I don't have difficulty seeing' which he qualified with 'but if a person is very far I don't recognise them. I just see it's a person. I think I have difficulty there when it's far – a distance from here to that tree. See that tree? When a person is there, I can't see who they are, but I can see if it's female or male.' When given the response options again and asked to confirm his response, he said he had 'some difficulty'. Respondent 10 (male, 64 years) reported 'no difficulty' and explained this as follows: 'I don't have difficulty seeing, but at night I can't read the bible or read small letters; but during the day I have no difficulty.' He

confirmed that he has 'no difficulty' by saying: 'I feel I have no difficulty because the time I work is during the day and seeing during the night I have no difficulty.'

The use of response options by respondents 5 and 10 reflects the grey area between reporting 'some difficulty' and 'no difficulty'. For respondent 10, the fact that he struggles to read small print at night does not create sufficient overall difficulty to warrant a response of 'some difficulty'. Respondent 5, on the other hand, does feel that not recognising someone at a distance constitutes 'some difficulty', but only after he has unpacked the activity and thought about it. He is clear what his 'some difficulty' refers to – far vision, a specific component of vision covered in a later question. Similar trends may be noted between the response options of 'some' versus 'a lot of difficulty', and 'a lot of difficulty' versus 'cannot do', but the sample of interviews is too small to provide enough examples to determine this.

5.1.2 Misinterpretation: responding to the 'even with glasses clause'

Respondent 6 (female, 39 years) said: 'No, I don't wear glasses. I have never tried them.' This respondent focused on and responded to the last clause of the question (wearing glasses). When this was clarified, she responded appropriately. This confusion was also noted in the WG/UNESCAP[37] project (UNESCAP 2010) and is a feature of this question that needs to be understood in analysing survey data across countries.

[37] As described in earlier chapters, the WG/UNESCAP was a project that undertook cognitive and field testing of the WG Extended Set questions in 2009. The project comprised 150 cognitive testing interviews in 10 countries, followed by field testing of the revised WG Extended Set in six Asia-Pacific countries. The countries were Cambodia, Kazakhstan, Maldives, Mongolia, Philippines and Sri Lanka for the field test and included Canada, USA, South Africa and Fiji for the cognitive testing interviews (UNESCAP 2010). Seven of my ten cognitive testing interviews were included in this study.

Table 5: Summary comments on intended meaning of questions

Questions	Intended meaning
1. Do you have difficulty seeing, even when wearing glasses? • No difficulty • Some difficulty • A lot of difficulty • Cannot do/unable to do	Ability to use eyes to see; if person uses glasses her response must be about difficulty seeing with his or her glasses, or without glasses if she does not have any.
2. Do you have difficulty hearing, even when wearing a hearing aid? • No difficulty • Some difficulty • A lot of difficulty • Cannot do/unable to do	Ability to use ears to hear; if a person uses a hearing aid their response must be about hearing with his or her hearing aid.
3. Do you have difficulty walking or climbing stairs? • No difficulty • Some difficulty • A lot of difficulty • Cannot do/unable to do	Ability to walk an unspecified distance and climb an unspecified number of stairs. The intention is report without use of any assistive devices but this is not controlled for in the initial question (it is in the extended questions which ask about difficulty with and without use of assistive devices.
4. Do you have difficulty remembering or concentrating? • No difficulty • Some difficulty • A lot of difficulty • Cannot do/unable to do	Ability to remember names, phone numbers, and do important things, etc. and concentrating on a task for an unspecified period of time.
5. Do you have difficulty with self-care, such as dressing or washing all over? • No difficulty • Some difficulty • A lot of difficulty • Cannot do/unable to do	Ability to use one's upper body to wash and dress, and some indications of being able to be independent in other self-care activities such as choosing appropriate clothes for different social and weather conditions.
6. Using your usual language, do you have difficulty communicating, for example, understanding or being	Using one's most frequently used language for understanding others and being understood – incorporating both receptive and expressive aspects of language use. Sign language would be

understood? • No difficulty • Some difficulty • A lot of difficulty • Cannot do/unable to do	included as a usual language for a Deaf person.
7. How often do you feel worried, nervous or anxious? • Daily • Weekly • Monthly • A few times a year • Never	Feelings that are seen as being out of the ordinary and beyond minor ones, such as mild anxiety before embarking on a journey.
8. How often do you feel depressed? • Daily • Weekly • Monthly • A few times a year • Never	Feelings that are seen as being out of the ordinary and beyond minor ones, such as mild depression after failing an exam or feeling 'blue' occasionally.
9. Do you have frequent pain? • Yes • No	Pain that is intrusive and causing significant discomfort
10. Do you have frequent feelings of being tired? • Yes • No	Fatigue and exhaustion beyond feeling tired after running a marathon or after a long day of physical work.

Only one respondent wore glasses (Respondent 1) and one other (Respondent 10) had tried to use glasses with no apparent benefit. This finding is consistent with both the number of respondents with any difficulty as well as the economic conditions of the respondents, who had few resources to obtain glasses. Seven of the ten respondents reported 'no difficulty' with seeing, one reported 'some difficulty', one 'a lot of difficulty' and respondent 3 provided no codeable response.

In conclusion, the evaluation of the first question on vision shows it to be a good question. It performs well and elicits responses that are consistent with the intended meaning of the question. The intention is to measure functioning in vision and this question will provide valid information for the population represented by the sample of respondents interviewed in Agincourt. The WG/UNESCAP cognitive and field testing of these questions in six Asia-Pacific countries (UNESCAP 2010) confirmed that this question performs well across a number of different countries.

5.2 Hearing

The WG first question for hearing was 'Do you have difficulty hearing even when wearing a hearing aid?' The WG Extended Set asked further questions focusing on hearing in a quiet room and hearing in a noisier room. Hearing in noise is more difficult than hearing in quiet and should pick up more people with difficulties than the question on hearing in a quiet room. A sound that interferes with one's hearing will be noted as noise, and this may vary from one person to another.

5.2.1 Understanding the intent of the hearing question

No respondents had any difficulty in hearing and the explanatory narratives show that respondents understand what hearing is. Narratives from Respondents 2 and 5 exemplify this.

Respondent 2 (male, 65 yrs):

I: Do you have difficulty hearing, even when using hearing aids?
R: Hearing - I still hear well
I: Explain what you mean by hearing well or not.
R: Because like now that you're talking, I can hear you well.

Respondent 5 (male, 70 yrs)

I: Do you have difficulty hearing even when you using hearing aids?
R: No, I don't have difficulty.
I: Do you use hearing aids?
R: No
I: How do you judge that you don't have any difficulty hearing? What do you think about when you say 'have difficulty hearing'?
R: Mmm… when someone speaks or whispers, I can hear what they are saying.

Respondent 10 (male, 64 yrs) describes a unilateral hearing loss. He reported 'no difficulty' as it does not cause him any noticeable problem overall. This is in line with the intention of the question which is to measure overall hearing functioning, rather than an objectively measured level of hearing by an audiologist. When asked to explain his response, he says 'I have no difficulty, but I have one ear that is not hearing properly. But the other one functions well. I can feel that when I close the other one.' When asked about the cause, he explained 'It started by having pains and there was something coming out of my ears. I was using a match stick, then it broke inside and it started giving me some pain, but it is no longer giving me problems now.' He reported 'no difficulty' hearing in a noisy environment.

5.2.2 Themes on understanding hearing questions: Hearing in noise

The main theme arising from the narratives was the issue of noise and its impact on hearing and listening. Two respondents (Respondents 5 and 7) did report some difficulty with noise, but only if the noise was quite loud.

When Respondent 5 (male, 70 yrs) is asked about hearing in noise he says he has 'some difficulty':

R: Oh, it troubles me. I don't like a room with noise. I don't know what to answer.
I: Does it make it difficult for you to hear if you are in a noisy room?
R: Yes
I: Is it a lot of difficulty or some difficulty?
R: It's some difficulty.

Thequestion on hearing does not specify whether the context is one with or without noise, as it is a more general question for use on censuses rather than more detailed surveys. The further questions on hearing in quiet and hearing in a noisy room address the more specific aspects of hearing.

Respondent 5 reported 'no difficulty' on the main question but 'some difficulty' in noise; in other words, in noise it is more difficult to hear. This response pattern is similar to that found on the WG/UNESCAP results from field testingof these questions (1000 respondents in each of six countries). The first question on hearing yielded slightly more respondents with any difficulty (10%) compared to the question on hearing in a quiet (7%), but less than for the question hearing in a noisy room (15%)(UNESCAP 2010). These results (Respondent 5 and WG/UNESCAP) suggest that the general hearing question is referring to hearing under conditions that are neither very quiet orvery noisy, but probably somewhere in between.

Two respondents (Respondents 2 and 3) reflected on the difference between noise that one can control, such as askingfor the radio to be turned down, compared to noise that one cannot control. The noise that one can control does not cause difficulty because of the ability to alter it, for example, by reducing theradio volume. Noise that cannot be controlled or altered is problematic precisely because it cannot be managed.

Respondent 2 (male, 65 yrs) describes this difference:

> R: In a house that has noise, you can't hear. Just like now that they switched on the radio - if they increase the volume you can't hear because you are hearing a lot of different things.
> I: Do you have difficulty or not?
> R: It's not a difficulty because that person is doing it on purpose.

In conclusion, the evaluation of the first question on hearing shows it to be a good question. It performs well and elicits responses that are consistent with the intended meaning of the question. The fact that none of the respondents reported difficulty with hearing on the first Short Set question, but often described some difficulty when there was noise, underscores that this question measures hearing in quieter rather than noisier conditions, as was found in the WG/UNESCAP testing (UNESCAP 2010). The intention is to measure functioning in hearing and this question will provide valid self-reported information for the population represented by the sample of

respondents interviewed in Agincourt. The WG/UNESCAP cognitive and field testing of these questions in the six Asia-Pacific countries (UNESCAP 2010) confirmed that this is a good question.

5.3 Mobility

The WG first question for mobility was 'Do you have difficulty walking or climbing stairs?' This section has the most questions in the WG Extended Set and tends to be the domain of difficulty most commonly reported as difficult.

5.3.1. Understanding the intent of the questions on mobility

Of the ten respondents, six reported 'no difficulty', and a seventh respondent 'some difficulty' intermittently and only on climbing because of asthma (Respondent 5). These seven respondents provided good descriptions, examples and explanations that concurred with their responses, and reported 'no difficulty' on the subsequent questions on walking 100 metres, walking 500 metres or climbing a flight of stairs. The remaining three respondents reported 'a lot of difficulty' on all questions (Respondent 1), varying difficulty for the set of questions (Respondent 2), and no clear responses (Respondent 3).

5.3.2 Themes in understanding the mobility questions

The themes described below are all within scope of the intended interpretations for the question on walking and climbing stairs. They are not misinterpretations. Understanding these different themes helps us understand the resulting statistics on mobility and interpret them meaningfully.

a) <u>A continuum of difficulty</u>

The response pattern of Respondent 2 (male, 65 yrs) showed a progression of difficulty : 'no difficulty' walking 100m, unspecified difficulty walking and climbing stairs for the first question, 'a lot of difficulty' climbing stairs or a small hill, and 'unable to' walk 500m. This profile of responses reproducesa continuum of difficulty noted in the field testing results of the WG/UNESCAP (UNESCAP 2010). Walking 100m requires the least mobility, followed by climbing stairs, and walking 500m. The

first question combining walking and climbing, did not elicit a clear response from Respondent 2, which could be explained by the lack of a distance reference and the combination of the two activities – walking and climbing. But he does suggest having a degree of difficulty, albeit unspecified. This suggest some but not a lot of difficulty. Other respondents did not replicate this continuum in their responses, largely because of not having difficulty or having 'a lot of difficulty' on all the questions. The results of the WG/UNESCAP study were for a large sample, allowing this pattern of a continuum to be more evident than in my small sample of ten interviews (UNESCAP 2010).

b) Geographical reference group effect

The notion of a reference group effect occurs when a person responds to a survey item using, as a reference, the characteristics of the group to which they belong. This has been documented in particular for subjective ratings of attitudes and agreements/disagreement with statements, typically in Likert scale items (Heine, Lehman, Peng & Greenbolt 2002; Albaum 1997). Respondents apply the cultural norms and belief of that group in choosing their response. An example of an attitude statement would be 'disabled people are treated the same as non-disabled people.' The measures I evaluated are not the same as Likert scale items, as they ask about a level of functioning and not agreement or disagreement with an attitude. However, the first mobility question raised another type of reference group effect – what I will refer to as a geographical reference group effect. This effect was also noted for the question on lifting a 2 litre jug as part of the self care domain discussed later in this chapter.

The context of Agincourt, as described in Chapter 3, requires large distances to be covered between villages and to access health care services. Transport is expensive and limited. The respondents' reference is that of walking long distances on a regular basis. Their responses to the WG Short Set question on 'walking and climbing stairs' is relative to this reference. The reference group is 'people

who have to walk long distances'. They reported difficulty walking, but when asked to explain their responses, gave example of walking distances of five to 20 kilometres. Because the question on 'walking and climbing stairs' does not specify a reference, this reference group effect may explain differences between contexts such as AHPU and ones where there is good transport and little need to walk long distance.

Respondents 7 and 8 described how they were not able to walk as far or as fast as when they were younger, but still described walking distances far longer than 500m. This reflects a perceived loss of ability which leads the respondent to report having difficulty. However, if measured objectively, these respondents would not have any difficulty as they are able to walk 100 metres, walk 500 metres and climb a flight of stairs. If only the first question is asked, these respondents would be counted as having difficulty, but if all the questions are asked, these two respondents may be excluded at the data analysis stage as they would be deemed as having 'no difficulty'. This is a good example of the value of asking the extended questions and of understanding these interpretations when undertaking the data analysis. Respondent 8 (male, 62 yrs) did not report difficulty but still reflected a loss of some ability to walk long distances without getting tired: 'I can walk but it's just that nowadays I cannot walk a long distance. But I can walk from Agincourt to here. [about 20 kms] without feeling tired'.

Respondent 7 (male, 60 yrs) did report difficulty, but this was relative to what he could do when he was younger. He seemed to reflect this in his struggle to find a suitable response to the first question, but not for the subsequent more specific questions. The response coded for the first question was 'no difficulty' but the initial narrative suggested more likely 'some difficulty', as exemplified in the quote below for Respondent 7.

Respondent 7 answering about difficulty walking and climbing stairs:

> R: Er…because I'm now old, it's no longer the same as the time when I was going, like walking from home [Mozambique] to here. It's no longer the same as when I was still younger because my knees were still strong.

I: Does this mean you have some difficulty walking and climbing steps because you are old, or does it mean you don't have difficulty?
R: I can walk but I cannot walk like before. Previously I use to run but now I cannot run from here to there because I'm old, but when I was still a boy I used to run for a long distance.
I: Does this mean you have some difficult or no difficulty?
R: Yes, because it depends on the age – becausewe cannot run the same. [not giving a clear response, but suggesting 'some difficulty']
I: The way you are explaining, does it mean that you have difficulty walking compared to the time you were young, as well as climbing the steps? Do you have difficulties? Actually we want to know if you have difficulty, some difficulty or no difficulty walking and climbing steps at the moment?
R: But I can walk for long distance but when I come back I just feel tired. [suggesting 'no difficulty'].

The exclusion of respondent 7 in the analysis of who has difficulty is done in a transparent and informed manner. The first question is from the WG Short Set, and if this set is used alone, for example, in censuses, the interpretation of the data would need to be mindful of this type of reference group effect that may explain some of the differences across countries with very different geographical contexts in relation to walking and climbing stairs. A similar finding was noted for the responses in the Maldives, one of the WG/UNESCAP study participating countries, where islands outside of the capital city island, were not more than two metres above sea level, and the respondents, hence did not have experience of climbing stairs.

c) Impact of ageing and pain on walking and climbing stairs

Related to the notion of a reference group is the impact reported by respondents of growing older and being in pain. Respondent 1 (female, 55 yrs) reported 'a lot of difficulty' on the main question (see quote belwo), which is consistent with her narrative. Furthermore, she provided a range of responses ('some difficulty' through to 'unable to do') for the extended questions on mobility. Her narratives also explained her difficulty in relation to the fact that she usually walks fast but finds that if she does walk fast her leg hurts. Her response of 'a lot of difficulty' reflects her perceptions of a difficulty (a change from her usual or desired ability to walk) that may not be the same as an objective measure, such as a timed walk over a specific distance with standard reference scores of

good and poor walking ability. On a standard objective measure of the distance that she can walk in a given period of time, for example, she may not have difficulty. This is a good example of the importance of, firstly, understanding what respondents are thinking about when they respond; and, secondly, complementing self-report information with objective assessments to obtain a holistic picture. This holistic picture, however, is not always possible on a large scale.

Respondent 1 (female, 55 yrs old):

> R: If I walk slowly, I have less difficulty but if I walk fast I have a lot of difficulty and I have to sit down. I used to walk fast but because of the leg [that hurts], I am unable to walk fast.
> I: So according to how you walk now, is it a lot of difficulty or less of difficulty?
> R: I feel I have a lot of difficulty because I'm not used to walking slowly. And also asthma stops me going fast, as well as the leg stopping me immediately if I try to be fast.
> <u>When asked if she can walk 500m</u>:
> R: With that I don't know because I have never done it before.
> I: Looking at the distance you walked from the clinic yesterday to here - would you say it was a lot of difficulty or some difficulty?
> R: It was a lot of difficulty because I was walking a short distance and getting some rest.

Respondents 7 and 8, described in the geographical reference group theme above, compared their ability now (which is good) to that when they were younger, such as when Respondent 8 (male, 62 yrs) referred to 'nowadays I cannot walk a long distance', and Respondent 7 (male, 60 yrs) says: 'It's no longer the same as the time I was going, like walking from home (Mozambique] to here [Agincourt]. It's no longer the same as when I was still younger, because my knees were still strong'.

All three of these respondents compared themselves to a point earlier in their lives when they were younger (respondents 7 and 8) or without pain (respondent 1).

d) <u>Distance references and interpretation of steps</u>

Providing a distance reference is clearly important, as the discussion on geographical context above shows. However, specific distance references need to be understood in order to be useful. The understanding of these distance references (100m, 500m, a flight of stairs) were not correctly understood by all ten respondents. Respondent 1 said she was 'not sure' about 100m, and 'doesn't

know 500m'. However she reported walking distances of more than 500m regularly. Her lack of 'knowing' the distance does not affect the survey response she gives. Respondent 3 focused on the example of the distance of one side of a soccer field for 100m and round a whole soccer field for 500m, rather than the distance itself and said she did not go to soccer fields. She needed much repetition and explanation and still was not able to provide a useful survey response. Other respondents were clear on the distance and responded confidently as did Respondent 7 (male, 60 yrs): 'A soccer field is too small [a distance]. It doesn't mean a thing to me' [he has no difficulty]. Respondents 2 and 4 were not clear on the references for steps and either thought of or asked for clarification on whether these were steps on a step ladder.

e) Aetiologically neutral activity limitations

One of the basic tenets of the ICF (WHO 2001) is that impairments, activity limitations and participation restrictions are neutral with respect to their aetiology. A person's difficulty with walking may be due to, amongst other reasons, a spinal cord injury, an amputation, severe illness and weakness, or negotiating a difficult terrain. The underlying health condition or aetiology is different but the outcome is the same – difficulty walking.

This aetiological neutrality was apparent across the ten respondents. Respondent 1 and 5 both mention the effect of having asthma on their ability to walk. Respondents 7 and 8 referred to the effect of ageing, and Respondent 1 also refers to the effect of pain. Respondent 5 (male, 70 yrs) reported 'no difficulty' walking but 'some difficulty' climbing steps. His overall response to the main question is 'no difficulty', which he then qualifies separately for walking and climbing. When asked about walking and climbing in separate questions, he reports 'no difficulty' in walking and 'some difficulty' in climbing steps and provides the following explanation: 'My difficulty is me not being able to breathe. It's not my legs. My legs are alright but it's breathing which makes me not able to

walk. ….If I start not breathing properly I have to stop walking. …I have difficulty breathing, not walking.'

In conclusion, the evaluation of the first question on mobilityshows it to be a good question but this performance is improved with the use of subsequent questions, especially in a context where people have little access to affordable transport and walk long distances, as is the case for the ten respondents. There were no instances of misinterpretations of the first question. The question responses and associated narratives are consistent with the intended meaning of the question. The intention is to measure functioning in mobility and this question will provide valid information for the population represented by the sample of respondents interviewed in Agincourt. The WG/UNESCAP cognitive and field testing of the mobility questions in six Asia-Pacific countries (UNESCAP 2010) confirmed that this is a good question.

5.4 Cognition – remembering and concentrating

The WG first question for cognition was 'Do you have difficulty remembering or concentrating?'

5.4.1 Understanding the intent of the Cognition question

This domain was the one with the most problems in interpretation. The intent of the question was misinterpreted in the same by six respondents. The remaining four respondents understood and interpreted the first question correctly. Respondent 2 (male, 65 yrs) correctly interpreted the questions, reported 'no difficulty' and described remembering in the following terms: 'remembering that I have to make bricks with that brick maker'. Respondent 5 (male, 70 yrs) reported 'some difficulty' because 'what can happen is that, there are times when I don't remember people's names like "Nicolas" ' and went on to justify that it is only 'some difficulty' because 'I don't take long to remember what I forgot'. The respondents who correctly interpreted the question made reference to remembering things to do or names of people, both memory functions.

The six respondents, who misinterpreted the question, all failed, in addition, to give clear responses that could be linked to one of the response options provided. Their narratives focused on thinking about sad events or difficult circumstances (emotional remembering or ruminating) rather than memory function as intended by the question.

5.4.2 Misinterpretations of the cognition questions

a) Emotional remembering and ruminating

There was only one type of misinterpretation which is significant in itself and simplifies, in a way, the recommendations for revisions, as these only need to address one problem. The second point discussed here (see b) below) provides an additional explanation based on respondents' demographic characteristics for the misinterpretation.

While the intent of the question is about difficulties in the function of remembering to do things or people's names, six respondents interpreted this as remembering or thinking about someone or something, such as the death of a loved one or difficult circumstances. Respondent 1 (female, 55 yrs) responded to the question as follows:

Respondent 1:

> R: When remembering bad things I have difficulty…
> I: Continue.
> R: My remembering brings all the memories and I start crying because I don't know what will help me get through that. That's what is difficult for me but when I have nothing to remember I feel good.
> I: How much difficulty do you have - is it some difficulty or lot of difficulty?
> R: It's a lot of difficulty in my heart.

Her focus was on ruminating about sad events that make her cry, as remembering, for her, is about problems with sad memories. The comments about feeling good when she has nothing to remember suggests that remembering is about thinking too much and having many sad things to think about. Patel and colleagues (2001) comment that, in Zimbabwe, 'most depressed individuals attribute their symptoms to "thinking too much", to a supernatural cause, and to social stressors' (quotes in

original). The question on remembering and concentrating is interpreted as being about this 'thinking too much' and closely related to feelings of sadness and anxiety. Other respondents gave unclear responses to the initial question, and, when asked about difficulty remembering important things, provided responses that focus on 'thinking too much' and ruminating. Respondent 7 (male, 60 yrs) referred to concentrating and remembering interchangeably and described them in similar terms:

Respondent 7:

> R: Sometimes I concentrate on doing something, such as doing something using my hands. I do concentrate and finish it but when it is something that involves money, I struggle to concentrate because I don't have money.
> ….
> I: Can you explain what is it that involves money that you cannot concentrate to do, can you explain what is it like?
> R: Something that involves money?
> I: What you were saying, that involves money.
> R: It's too much. Even here at home many things need money. I just say it in my heart [think about it] but I cannot do anything because I don't have money. This can be like building a house. But going to the bush to cut / fetch grass or wood it is easy to concentrate doing it unlike something that involves money.
> <u>When pushed to use the response options</u>:
> R: A person cannot get tired remembering, as we live in this earth. But you fail to remember [concentrate?] if it involves money, because you don't have it.But if doesn't involve [money] it's easy to remember because you can afford to do it.

Respondent 8 (male, 62 yrs) reported 'no difficulty', but when pushed for an explanation on remembering important things, he resisted using the response options and gave a narrative of remembering the difficult context of having lost his job. He concludes with the comment that these problems arise because 'as a person, you think'.

Respondent 10 (male, 64 yrs), when asked for the reason for his difficulty, explained that it was mostly because of 'thinking too much'. Respondent 1 (female, 55 yrs) described the impact of her difficulty as limiting her because 'when I start remembering [problems with my husband], I immediately get tired and sit down.' She makes a clear link between this ruminating or thinking

about her problem and feeling fatigued, a link which is developed further in the discussion on the fatigue questions below.

The results of the 150 cognitive testing interviews analyzed for the WG/UNESCAP study (UNESCAP 2010) showed that, while 60% of respondents reported 'some' or 'a lot of difficulty' remembering or concentrating, the theme of emotional remembering only appeared in the narratives of my ten interviews. This may be due to the lack of detail provided in the narratives of some of the other respondents or a specific feature of how this question is interpreted in southern Africa, based on my findings and those reported by Patel and his colleagues in Zimbabwe (2001). I asked a fluent speaker of Shangaan and experienced translator[38] to translate the Shangaan version of the question (difficulty remembering or concentrating) back into English. I did not show him the original English version. His translation included the phrase 'someone or something' as the object of remembering. He explained that the verb 'to remember' in Shangaan is transitive and, thus,always requires an object (someone or something) to remember. This is substantiated in the translations of the interviews where the question was often translated back into English not as 'remembering and concentrating' but remembering something or someone. In English, the sentence 'I have difficulty remembering' is logical and complete and can function as both a transitive or intransitive verb[39], whereas in Shangaan it is only complete when the person or thing being remembered is added.

This interpretation related to 'thinking too much', as described by Patel and his colleagues (2001) in Zimbabwe, associates two domains of functioning, namely, cognition and depression. Aidoo and Harpham (2001) show how concepts of stress and depression are commonly described by women in Zambia as being 'problems of the mind'. This provides another layer of explanation for the

[38] Dr Theo Schneider, translator of the Bible into Shangaan and fluent speaker of the language.

[39] For example, one can remember, as in 'I have difficulty remembering' or one can remember something or someone as in 'I remember that person'.

misinterpretations. From my results, I propose that the misinterpretation of the remembering and concentration question as 'thinking too much' or 'something of the mind' is a product of a translation concern combined with a strong salience of sadness, heartache and the context of hardship experienced by the six respondents. When faced with reporting on difficulties remembering, the first thought that came to the six respondents was about the difficulty of emotional remembering.

The notion of idioms of distress provides a further explanation for these misinterpretations. Idioms of distress are ways that people express or mark their distress, usually through reporting difficulties with affect, pain, cognition and sleep (Scobar, Avier & Gureje 2007; Gureje 2007; Gureje, Ogunniyi, Kola & Afolabi 2006; Miranda et al 2005; Patel et al 2003; Patel et al 2001; Patel 2001; Moussavi et al 2007). The expression of distress is referred to an as idiom as it is expressed in culturally specific ways. Reporting difficulties in remembering and concentrating could be a way for the ten respondents to express their distress. There were no obvious references made to culturally specific expressions of this distress in the responses, but this may have been due to pre-empting th s by asking the question itself. In-depth interviews that asked respondents to describe problems in their lives and their health may have elicited such examples. The cognitive testing interviews were specifically focused on asking the questions. I discuss this notion of expressions of distress in more detail in Chapter 7 as it is also of relevance to the domains of affect, fatigue and pain.

b) <u>Explaining the misinterpretation with demographic characteristics</u>

A further explanation is the age, education and socio-economic characteristics of the ten respondents, as summarized at the start of Appendix 5. Five of the six respondents,who misinterpreted the question, had no or only primary education and four were classified as having a low socio-economic status. (The relative nature of the socioeconomic status is explained in Chapter 3.) Respondent 4's household was classified as 'high' socioeconomic status, but had no formal education and was a Mozambican national. Respondent 1 was the exception out of the six

respondents, as she lived in a household with a 'high' socioeconomic status, had completed some secondary school education and was South African. However, during the interview, she complained frequently about her problems with her husband. The four respondents, whose interpretations were congruent with the question intent, all had primary or secondary education, were all from households classified as 'high' socio-economic status, and two were South African and two Mozambican.

Loosveldt (1997) concludes from his analysis of interviewer-respondent interactions that age and education combine as factors that affect the ability of respondents to answer survey questions. Older and less educated respondents had more difficulty answering questions than younger and more educated ones. Miller (2003) concurs and adds low socio-economic status as an important factor determining responses. She (Miller) strongly advocates for cognitive testing of survey questions specifically with people from people with low education and poor living conditions.The characteristics of the six respondents are in accordance with the factors of age, low education and being poor. Being Mozambican may be an additional factor in the Agincourt area and may signify an additional source of hardship, as Mozambicans came to South Africa as refugees from war torn Mozambique. The length of time they had been in South Africa would also vary. Respondent 10, for example, had been in South Africa for over two decades. The evidence from my interviews is not conclusive, and may suggest that it becomes a compounding factor together with age, education and low socioeconomic status, rather than a factor on its own.

5.4.3 Double barrelled structure of the question

It is not good practice to ask a double-barrelled question in surveys, but the results of the UNESCAP/WG testing of this question suggest that this does not pose a problem for this question (UNESCAP 2010). The findings in the WG/UNESCAP study showed that the majority of respondentswith difficulty reported difficulty in remembering, followed by difficulty in both remembering and concentrating, and only a few reported difficulty in concentration alone. As the

difficulty reported on this question increased, so the difficulty on both aspects increased, underscoring the close relationship between remembering and concentrating. The possible reasons for these findings are given as concentrating being: 'a) a more robust mental function than remembering and thus less difficulties arise; b) a developmental function that is consolidated in adulthood while memory is less developmentally influenced.' (UNESCAP 2010, Cognition Chapter: 9).[40] The latter reason is borne out by the higher percentage of younger respondents (0 – 17 year old) reporting concentrating difficulties compared to all other older age groups. TheUNESCAP report concludes that 'this does imply a consistent correlation between the two cognition items, supporting the argument that the double barrelled structure of [the question on difficulty remembering or concentrating] is not a problem and that these two aspects of cognitivefunctioning should remain in a single question.' (UNESCAP 2010, Cognition Chapter: 10).

The results from my ten interviews showed some differentiation between responses for remembering and concentrating, interchangeable use of the terms, or ignoring one aspect. None of the ten respondents gave any indication of being confused by the double-barrelled structure of the question.

In conclusion, for Shangaan speakers, this question did not perform well and requires revision as described above. A way to avoid the misinterpretation of the question on remembering and concentrating would be to give the respondents clear references to clarify the question intent, such as examples of remembering what needs to be done each day, remembering people's names, and remembering to take medication. The Shangaan translation should clarify the difference between difficulty remembering things, such as doing chores, taking medication or people's names, and difficulty *because* of remembering things, such as the lack of financial security, loss of a loved one or

[40] This reference includes the specific Chapter as the report is presented on the website as separate chapters and not as one whole report. The page reference refers to the pages in that Chapter.

other difficult life circumstances. The respondents are clearly conflating having trouble remembering with being troubled by memories. The large number of respondents with the same misinterpretation makes the revision simpler to address than if there were a wide range of different misinterpretations.

5.5 Self-care and upper body mobility

The WG first question for self-care and upper body mobility was 'Do you have difficulty with self-care such as washing all over or dressing?' The self-care question in the Washington Group Short set was developed in part to provide a measure of upper body mobility, in that washing and dressing both require mobility in the fingers and arms. In Agincourt, as described in Chapter 3, the main source of water is a communal tap. People bring large 25 litre containers to fill up at these taps, load them onto wheelbarrows and push the wheelbarrow home.

5.5.1 Understanding the intent of the question on self care

All ten respondents interpreted the questions on self-care and upper body mobility correctly and all reported 'no difficulty'. Respondent 1 (female, 55 yrs) was quick and clear in her responses (see quote below) and included two brief pieces of narrative to indicate her understanding of the question, reiterating that she does bath and dress and saying that her problem is with her legs and not her hands.

Respondent 1:

I: Do you have difficulty with self-care such as bathing all over or getting dressed?
R: I have no difficulty - I do bath myself and get dressed.
I: Do you have difficulty lifting up a 2 litre container of water from the waist to eye level?
R: No, I have no difficulty
To clarify if she can lift a 2 litre jug of water:
I: If you get a 2 litre coke bottle can you lift it up?
R: Yes, I can lift it up. My only problem is the leg – my hands are fine.

Respondent 3 (female, 72 yrs), despite difficulties answering most other questions, was able to provide a clear response to the first question on washing all over or dressing. In her narrative, she seemed to understand 'lifting' a two litre jug of water as 'carrying' but then said quite clearly that she had 'no difficulty' when the example was clarified in the discussion.

Respondent 10 (male, 64 yrs) was clear in his responses (see quote below) and indicated that a two litre jug of water is nothing to lift up as he regularly lifts 25 litre containers of water. This is a further example of the possible effect of geographical context discussed for the mobility domain above. The effect was not evident for the domain of self care as no respondents reported any difficulties.

Respondent 10:

> I: Do you have difficulty with self-care such as washing all over or getting dressed?
> R: No difficulty.
> I: Do you have difficulty lifting a 2 litre container or jug of water from the waist to the level of your eyes?
> R: Even the 25 litres container, I can raise it, holding it by here and here.
> I: (Laughing) Does this mean you have no difficulty raising a 2 litre jug?
> R: Yes

A two litre jug of water was a very small container in comparison to what these rural dwellers carry on a daily basis to fetch water from the communal taps. A couple of respondents initially were confused by the two litre reference and seemed to immediately think of their usual 20 or 25 litre containers. They thus reported some difficulty lifting these large containers. When the container size was clarified, these respondents said they had 'no difficulty' lifting the two litre jug of water.

Typically, difficulties on self-care reflect a significant level of difficulty usually involving other domains, such as seeing, cognition, and mobility (Schneider et al. 2009; Cambois, Robine & Romieu 2005). The respondents in this study were all people living at home and all functioning independently, which is congruent with the responses given to this question.The respondents who would typically report difficulties with self-care, where this was not a severe difficulty, would be

people with missing arms or hands or limited functional use of one or both upper limbs. None of the ten respondents had any problems with their hands and/or arms.

The first (main) question was about self-care, with the examples of washing and dressing. The implication is that self-care requires upper body mobility. The extended question, asking about difficulty lifting a two litre jug from waist to eye level, was included in the WG Extended Set to specifically consider arm mobility. Respondents all reported 'no difficulty' for this second question.

In conclusion, the question on self-care performs well and is interpreted correctly. The statistics generated from this question will give a good measure of self-report levels of self-care functioning.

5.6 Communication

The WG first question for communication was 'Using your usual language, do you have difficulty communicating, for example, understanding or being understood?' The focus of the question is on the ability to express oneself and understand others through language. The notion of communication is closely related to, but not the same as cognition. People with cognitive problems, for example, Alzheimer's disease, can often produce language but the flow of conversation loses its logic and they are not able to understand what people are saying beyond some automatic language functions, such as greetings. None of the ten respondents were cognitively impaired, as they all were able to take part in the interview process and lived at home. The lack of any communication difficulties also reflects the observed ability of all ten respondents to communicate effectively during the interview.

5.6.1 Understanding the intent of the question on communication

None of the respondents reported any difficulty with communication, but a couple had a few difficulties in understanding the question. Respondents who understood the question, and gave relevant examples and explanations in their narratives, answered with clear responses.

5.4.2 Themes in understanding communication

The two main themes noted in the way respondents understood the question on communication were about which language was being referred to as the 'usual language', and what communication entails.

a) What language is referred to by 'usual language'?

Respondent 1's narrative (female, 55 yrs) reflects that she understood the intent of the question as being about her usual language or 'my own language' (see quote below). This understanding was carried through to the second question about other people understanding her where she qualified her response with 'who know our language'.

Respondent 1:

> I: Using your usual language, do you have difficulty communicating, for example understanding others or being understood?
> R: I will not have difficulty using my own language because it is my own language; I can understand and be understood.
> I: You have no difficulty?
> R: No
> I: Do people have difficulty understanding you when communicating to them?
> R: Those who know our language will not have difficulty.

Respondent 8's narrative (male, 62 yrs) also reflected a correct understanding of the question intent: 'I don't have difficulty using Shangaan language. I have no difficulty I can talk and what the other person says, I can understand'. He feels he cannot comment on whether others understand him as he has never asked for feedback and no-one has told him if they do not understand him.
Respondent 10 (male, 64 yrs), on the other hand,was clear in his understanding of the question and added that people have no difficulty understanding him.

Respondent 5 (male, 70 yrs) provided a narrative asking for clarification (see quote below). He used more than one language and was not sure which one he should consider. When this was clarified, he had no problem responding to the question.

Respondent 5:

R: Your question, I don't really understand…I don't know what [you] want to know.
I: What part don't you understand about the question?
R: Which language you mean, because it's three languages that I use mainly?
I: Which one is your most comfortable language?
R: Shangaan
I: So in Shangaan
D: In Shangaan do you have difficulty understanding when you are spoken to in Shangaan, or if you are explaining to someone else,do they understand you in Shangaan?
R: No difficulty.
D: Do people have difficulty when you talk to them?
R: No

Respondent 6 (female, 39 yrs) showed in her narrative, that she had not considered the phrase 'usual language' in her response. When this was clarified, she was able to respond with ease.

Respondent 6:

I: Using your usual language, do you have difficulty understanding or be understood?
R: Yes
I: Do you have difficulty?
R: No I don't have difficulty. If it's Shangaan, it's fine, but I have a problem communicating in English.
I: Do people have difficulty understanding you when you speak?
N: No

Two respondents (Respondents 5 and 6) were not sure what language they should consider as their usual language. This was clarified and they were able to respond to the question. Their confusion arose because they were multilingual.

b) <u>What does communication mean</u>?

Respondent 3 (female, 72 yrs)interpreted the communication question as unburdening oneself emotionally and focused on communication as telling others 'what troubles my life'. She concluded with a response of 'no difficulty'. Her narratives are discussed in more detail in the case study presented below.

Respondent 3 was the only one out of the ten that did not interpret the question intent correctly.

In conclusion, the question on communication performs well and is understood and interpreted by respondents as intended. The single respondent who misinterpreted the intent (Respondent 3), did so by expanding the interpretation. Her narratives showed that she did understand the intent as being about communication and using language but added to her interpretation what she understood to be the main aim of communication – to unburden herself by talking about her problems. The WG/UNESCAP cognitive and field testing of these questions drew attention to a number of possible misinterpretations which were not noted in the narratives of my ten respondents. These misinterpretations included difficulty because of not speaking the language or being shy (UNESCAP 2010).

5.7 Affect: Anxiety

The WG Short Set does not have a question for either of the affect domains – anxiety and depression, because 'it is was deemed very difficult (if not impossible) to measure anxiety and depression using a single question. Rather than create a measure that is unclear as to what is being measured and most likely introduces a significant number of false positives, the decision was made to exclude this domain from the WG Short Set and develop it within the extended set' (UNESCAP 2010,Chapter on Affect: 1). Thus, the first question for anxiety is not from the WG Short Set. The questions for anxiety from the WG Extended Set were:

1. How often do you feel worried, nervous or anxious? Daily, Weekly, Monthly, A few times a year, or Never?
2. Do you take medication for anxiety?
3. Thinking about the last time you felt anxious, how would you describe the level of anxiety? Mild, moderate or severe?
4. Thinking about the last time you felt anxious, was the anxiety worse than usual, better than usual, or about the same as usual?

The focus of my analysis is on the first question, with supporting evidence from the other three questions. If the response to the first question was 'never' and no medication was taken, the remaining questions were skipped. These questions were towards the end of the questionnaire and were not always asked in their totality due to respondent fatigue.

5.7.1 Understanding the intent of the anxiety questions (by the respondents)

As discussed in Chapter 2, common mental health disorders, such as anxiety and depression, are important considerations for public health and prevalence is high in developing countries (Patel &Kleinman 2003; Lund et al. 2011; Havenaar et al. 2008). Anxiety and depression are closely related to poverty, and related to feelings of insecurity and hopelessness, rapid social change, and being at risk for experiencing violence and physical illness (Patel &Kleinman 2003). Cattell (2001) describes how people see health as being related to the death of loved ones, concern over not having enough resources to meet one's needs, and getting into debt. She raises another common thread in people's narratives around health – the role of social support for 'when things go wrong, or being able to talk about problems for example' (Cattell 2001: 1511).

The recording of common mental health disorders as part of disability statistics requires careful consideration of these different factors and relationships to ensure that we understand what is measured. The main question is whether we are measuring, primarily a medical condition requiring medical intervention, orprimarily a problem of poverty and lack of social support, which requires non-medical and broad interventions. The need for broad interventions, including social assistance, poverty reduction and increasing social support, is well recognised (Lund 2011; Patel and Kleinman 2003; Miranda and Patel 2005).

The questions on anxiety were interpreted correctly as evidenced by respondents' examples and descriptions reflecting emotional wellbeing. However, none reported severe anxiety or taking medication for anxiety. Five respondents reported 'never' feeling anxious, worried or nervous; two

reported anxiety ‘a few times a year’, one reported anxiety ‘weekly’, and two respondents did not provide sufficiently clear responses to assign a code.

Respondent 2 (male, 65 yrs) ‘never’ experienced anxiety and expounded on reasons why people would worry and be anxious.

Respondent 2:

> I: How many times do you feel worried, nervous or anxious? Is it everyday, weekly, monthly or a few times in the year or never?
> R: There isn’t - never.
> I: What can make other people worry?
> R: Things which make other people worry is that their family affairs are not well. They worry a lot becausethey don’t have food and other things. That’s the reason that will make them worry.

Respondent 4 (female, 53 yrs) reported problems only ‘a few times year’ and related this to being ill. She had diabetes and high blood pressure and took medication for these two conditions. When I asked if she took any medication for anxiety, she said she did, but then explained that these tablets were for the two health conditions, and not for anxiety as such.

Respondent 8 (male, 62 yrs) reported ‘never’ having anxiety and explained this as coming to terms with what he had, and so not worrying about not having what he needed.

Respondent 8:

> I: How often did you feel worried, nervous or anxious - is it daily, weekly, monthly, or few times in a year or never?
> R: Never
> I: What makes people get worried?
> R: Because of not getting useful things that are important to them.
> I: Do you get enough things?
> R: It’s not enough, but deep inside my heart I tell myself that what I have is enough for me.

5.7.2 Themes on understanding anxiety

There were fivemain themes evident in the narratives of the respondents, highlighting different aspects of anxiety. These were anxiety in relation to unmet need, due to unknown ‘things’ or

burglars, anxiety as a normal part of life, the inability to measure anxiety in degrees of severity, and anxiety as unrelated to health.

a)Anxiety in relation to unmet needs:

Respondents 7 and 8 described anxiety in relation to not getting things that one needs. Respondent 7 linked worrying about his children not getting jobs, despite having an education, and Respondent 8 (see above quote) explained why someone would get anxious even though he himself was not anxious. While the reported anxiety may be important to document, the decision on whether it is clinically significant anxiety or not remains unanswered by the measure itself.

Respondent 7 (male, 60 yrs) described what makes people, including himself, anxious: 'Everybody has to worry because when I'm always thinking I am worried. And when I just sit at home, I get worried because I don't get what I want. And as I mentioned, my children are not employed, that worries me. I'm worried when my children don't get what they've worked for'. He refers to worrying as the question uses that term in addition to anxiety. The term worry suggests a less severe feeling than anxiety and, his and other responses below, could be influenced by the use of that term.

b)Anxiety due to unknown 'things' or burglars:

Respondents 3 and 6 described events outside of their control as causing their nervousness or anxiety. Respondent 3 was worried about burglars as she had been repeatedly burgled and felt vulnerable as an elderly woman living on her own (see the case study below for more details)

Respondent 6 (female, 39 yrs) described a 'thing' coming onto her roof at night preventing her from sleeping. She described this not so much as creating anxiety but making her scared. She does not know what this 'thing' is and will not go and look at night as she is too scared to find out what it is. When I discussed this with my interpreter after the interview, he felt her response and fear was related to bewitchment or a curse. Her paranoia or fear prevented her investigating it: 'You will not go and see what it [thing on the roof] is during the night', and it was not there during the day.

c) Anxiety as a normal part of life and a necessary feeling:

Respondents 5 and 7 provided specific evidence of anxiety being both a normal and a necessary aspect of life. Respondent 7 (male, 60 yrs) says: 'a normal person will get worried sometimes because if you don't get worried it means that you don't have wishes. If you are normal you have to worry sometimes'.Respondent 5 (male, 70 yrs) explained anxiety as a normal and necessary part of being human and alive as 'we are born with anxiety. Even children have it'.

d) The inability to measure anxiety in discrete ratings of severiy

Respondent 5 did not use the given response options as he said 'I can't measure it' when asked whether his anxiety was mild, moderate or severe. Anxiety is an 'all or nothing' phenomenon and cannot be rated along a continuum of severity as required by the response options.

e) Anxiety as unrelated to health

Most of the respondents who reported having worry or anxiety said that this was not because of a health problem, which is congruent with the reasons for anxiety discussed above. Respondent 5 described anxiety as happening naturally and him 'not being sick' but just feeling anxious. Respondent 6 said it was not because of a health problem, but because of the 'thing' on her roof at night.

Respondent 7 gave two possible causes for anxiety: the death of a family member or close friend and when one is injured. He said he started having anxiety 'after getting married because when you are still a boy you don't have many problems – you start thinking [about your responsibilities] when you are married'.

None of the respondents with anxiety reported any impact of the anxiety on their daily life because 'it comes and goes' (Respondent 3), or 'it only comes at night' (Respondent 6).

5.7.3 Understanding what is measured with anxiety questions (by users of the statistics)

The analysis of responses to the anxiety underscores the potential problems of using such questions without a good understanding of how they are interpreted and answered by respondents in low income contexts, especially due to the close relationship between the respondents' narratives of poverty and their reported problems with anxiety. The link to the notion of idioms of distress, discussed above under cognition, is relevant for this and the other feeling domains (depression, fatigue and pain).

Some of the potential question evaluation concerns for the anxiety question include the following:

a) What is being measured? Is the intent of the question to measure any anxiety or anxiety which is out of proportion to the circumstances? A person living in dangerous circumstances may feel afraid all the time but this will have a different meaning from constant fear felt by someone, not living in dangerous circumstances, but because of a clinical anxiety disorder. The differences would be in relation to the primacy of the anxiety. Is it anxiety that makes life difficult to live, or a difficult life making one feel anxious?
b) Why are we measuring it? Do we want to know how many people exhibit a certain functioning difficulty, for example, to correlate with levels of poverty, or do we want to know how many would require medical treatment for this problem?

Anxiety and depression particularly, but also pain and fatigue (see below), are domains that reflect feelings that could arise from : a) normal feelings that people experience for short periods of time and with a known cause, such as fatigue after too much physical activity, or mild depression after a bad week at work); b) feelings that are long lasting that arise in reaction to one or more events in one's life, such as the death of a loved one, or unemployment); or c) feelings that arise due to a

chemical imbalance within the person. The narratives from the respondents provide some insight on the pathways to which the respondents attribute the cause of anxiety and depression.

This is important information as it goes directly to informing the type of intervention required. If a person is depressed because of external causes such as adverse life contexts, the intervention is not provision of medication for anxiety or depression, but rather a concerted effort to reduce the adverse conditions, such as increasing job opportunities, improving education, and providing equitable services. If these trends are clearly noted in the results, survey questions on anxiety and depression, and possibly other domains of functioning, can include further questions to try and identify the pathways of causality (as perceived by the respondent, of course). The resulting information can show the extent to which each pathway is prevalent in a sample population.

The main themes arising from the narratives on anxiety relate to unmet needs for survival, unknown 'things' that could be linked to bewitchment and burglars, or anxiety being a normal and necessary part of life. These cover two of the causal pathways described above – 'normal part of life' and exogenous or externally triggered feelings of anxiety. Unless a respondent has been given a specific diagnosis of 'anxiety disorder', it is unlikely, especially in low resource contexts, that they would report such a specific disorder.

In conclusion on the questions on anxiety, the responses and the supporting narratives suggest that the respondents understand the scope of the question intent. However, the circumstances that trigger anxiety are described as broad and strongly related to the life context of the respondents, which includes lack of resources, fear of not being able to meet one's responsibilities, insecurity, and unknown 'things'. The measure is not able, and was never intended, to provide a clinical diagnosis of anxiety. It will, therefore, include people with both clinically significant and non-significant levels of anxiety into the statistical count. Other means, such analyses of response patterns over more than one question, can move towards a clearer delineation of these different levels of anxiety.

5.8 Affect: Depression

As for anxiety, the measurement of depression does not have a single question and is not included in the WG Short Set of questions. The questions on depression were as follows:

1. How often do you feel depressed? Daily, weekly, monthly, a few times a year, or never?
2. Do you take medication for depression?
3. Thinking about the last time you felt depressed, how depressed did you feel, a little, a lot, or somewhere in between a little and a lot?
4. Thinking about the last time you felt depressed, was the depression worse than usual, better than usual, or about the same as usual?

5.8.1 Understanding the intent of questions on depression

Six respondents correctly interpreted the questions on depression (2, 5, 6, 8, 9 and 10), while the remaining four respondents were unclear in their interpretations (1, 3, 4 and 7). Seven respondents (1, 3, 4, 5, 6, 7, 9) reported depression, with most reporting problems 'a few times a year'. Respondents 2, 8 and 10 gave clear responses of 'never' feeling depressed.

Respondent 6 (female, 39 yrs) struggled to understand the question, but was able to give a response that could be coded when options were repeated.

Respondent 6:

> I: How often do you feel depressed? Every day, weekly, monthly or a few times in a year or never?
> R: Huh?
> R: But you understand me when I say depressed?
> R: No
> I: Feeling depressed in the heart [provided as an explanation of depression].
> R: It's many times because when you live in this earth there is no way that you will not come across with problems.
> I: But does your depression happen daily, weekly…?
> R: Huh, sometimes I can even spend three months without being depressed.
> I: Is it few times in the year?
> R: Yes

5.8.2 Themes in the understanding of depression quesions

There were four themes evident in the respondents' narratives for depression. These were about depression being related to physical illness, caused by an outside agent or reason such as the death of a loved one, being part of normal life, and the inability to measure depression in discrete degrees of severity. These themes are similar to the responses for the questions on anxiety, and further reflect the close relationship between depression, as a common mental health disorder, poverty and related adverse life contexts.

a) Depression related to a physical illness

Respondent 9 (female, 69 yrs) struggled to grasp the intent and scope of the question (see quote below). I explained the intent and repeated the question. Her interpretation of depression was related to physical illness or a physical manifestation of depression as pain. She also described the use of a traditional medicine - a tea brewed from the bark of the marula tree.[41]

Respondent 9:

I: How often do you feel depressed… do you understand when we say depression?
R: Yes, when you get sick.
I: Not sickness, but feeling depressed but not to be ill. How often did you feel depressed, is it daily, weekly, monthly, few times in a year or never felt depressed?
R: In pain?
I: What do you understand by physical depression? What do you mean in other words when you say physically depressed?
R: When you have emotional problems, but you don't have to put them in your heart but make them easier.
[The question set for depression was started again]
I: How often did you feel depressed? Is it daily, weekly, monthly, few times in a year or never depressed?
R: Being depressed, it happens sometimes in a year. [a few times a year]
I: Do you take or use medication for depression?
R: If I am depressed, I use it.
I: Can you describe what you use when you are depressed? The medication you use.

[41]Marula trees are large fruit-bearing trees and are common in the Agincourt area.

R: Huh, even this bark [and the nut, called *timongo,* from the marula tree] I use them [points to a marula tree in her yard].

b) Depression caused by an outside agent

Respondent 10 (male, 64 yrs) reported 'never' feeling depressed and explained what he understood by depression. His response (see quote below) concurred with his understanding of depression as caused by the loss of a relative.Because he had not experienced such a loss, he reported 'never' feeling depressed. When pushed to explain further, he commented on life factors also playing a role, such as tension within the family and poor financial status. He made reference to his Christian faith as an important tool in managing depression when it did arise.

Respondent 10:

I: How often do you feel depressed? Is it daily, weekly, monthly, a few times in a year or never felt depressed?
R: I never had depression because depression comes when you have lost some relatives and it has never happened to me.
….
I: Do you have it [depression] sometimes?
R: Yes it might happen there and then. But I learnt a lot about it on the verse that says "be glad in the Lord always" so when I come across something I just ignore it.
I: Er… What is depression?
R: A depression is something that… depression is just an English word which means something that makes you feel depressed and not being well, like when a relative has passed away or you and your wife not understanding each other, or children when they do silly things. All of these can make you feel depressed; or maybe your financial status when you put all your mind to it [focus on it], this can make you feel depressed as well.
I: Do you use or take medication for depression?
R: No.

Respondent 1 (female, 55 yrs) described her depression as being caused by her husband not giving her enough money. She said that she was unable to change that.

c) Depression as part of 'normal life' and being human

Two respondents described how depression is part of what it means to be human. This is well described by respondent 6 (female, 39 yrs): 'It's [being depressed] many times because when you

live in this earth there is no way that you will not come across problems.' She described part of her depression being about not having enough food.

Respondent 7 (male, 60 yrs) said 'It happens because I think', which reflects the theme of 'thinking too much' (Patel et al, 2001) discussed under the cognition questions above.

d) Inability to measure depression in discrete ratings of severity

Respondent 7(male, 60 yrs) explained how depression cannot be measured: 'You cannot measure depression if it less or a lot because, all in all, you are depressed even if you are less depressed.'

Respondents 1, 5 and 9 said that depression did have an impact on their daily activities, such as ploughing and cooking. Respondent 1 (female, 55 yrs) explained this impact: 'because when I'm working and I feel it [the depression], I just leave everything.'

In conclusion, the narratives describing respondents' interpretations and understanding of the depression questions reflect very similar themes to those for the questions on anxiety. This is consistent with the common co-existence and elusive nature of these two problems. The discussion on what is being measured with anxiety has relevance for the domain of depression as well.

5.9 Pain

The pain questions are not included in the WG Short Set as it is difficult to get a good measure of pain using a single question. Pain is not an activity as such but does affect people's functioning significantly and, hence, can be used as a potential proxy for problems in functioning. Furthermore, it is a commonly occurring feature of people's lives.

The questions asked for pain were:

1. Do you have frequent pain?
2. Do you use medication for pain?

3. If yes to 1 or 2**:** In the past 3 months, how often did you have pain? Some days, most days, or every day?
4. Thinking about the last time you had pain, how long did the pain last? Some of the day, most of the day, or all of the day?
5. Thinking about the last time you had pain, how much pain did you have, a little, a lot, or somewhere in between a little and a lot?

5.9.1 Understanding the intent of the pain questions

Four of the respondents (2, 6, 9 and 10) provided clear and correct interpretations of the first question on frequent pain. Three respondents (1, 3 and 7) did not provide sufficient information to conclude on their interpretations of frequent pain and the response option to be coded. The last three respondents (4, 5 and 8) did not provide enough information to be sure of their interpretations, although they provided clear responses of no frequent pain.

Respondent 2 (male, 65 yrs) reported no frequent pain (see quote below), but described occasional pain that he managed with medication. His responses concurred with his descriptions and showed that he has understood the point about pain being frequent, and not any pain.

Respondent 2:

I: OK, do you have frequent pain?
R: No I don't have frequent pains
I: Do you use medication for pain?
R: Yes, when I have pains, I use tablets [from hospital].
I: How often do you have pain?
R: It's not often it happens – here and there
I: How often did you have pain, is it some day, a lot of days or everyday?
R: It's not every day.

Respondent 9 (female, 69 yrs) reported 'sometimes' having pain but said 'no' when asked if it was frequent. This respondent also understood the point about the pain being frequent: 'No, it's not frequent but I just feel it sometimes'.

Of all respondents, eight reported no frequent pain (although some did report occasional or event specific pain), and two reported having frequent pain.Respondent 1 (female, 55 yrs) focussed on her pain related to a recent spate of boils and did not provide further explanations on any other pain. Her narrative was not clear on whether the pain was frequent or not. She uses medication for pain (brufen) and describes more than one site of pain. Her answers are clear, but in her response to the first question, she does not refer to obviously frequent pain. Her reference to the pain from the boils was limited in time although recent (a month before the interview was done), and her pain related to her leg seems to be more long standing albeit intermittent.

Respondent 3 (female, 72 yrs) was consistent in her inability to provide a focused response using the given response options. However, her long narrative showed that she understood the intent of the question, but was not able to use the response options to guide her to a specific coded response. This is discussed further below in the case study.

5.9.2 Theme on the understanding of pain questions: physical vs emotional pain

The main theme in relation to pain responses was that of physical versus emotional pain. While the domain of cognition brought up the interpretation of 'emotional remembering', only two respondents (6 and 1) in the pain domain referred to emotional pain. Respondent 6 (female, 39 yrs) asked: 'Doyou mean emotional [pain]?' and Respondent 1 referred to emotional pain caused by her husband. All respondents who provided elaboration on their responses gave physical examples of pain, such as an ulcer, a broken arm, and headaches.

All three respondents (Respondents 1, 2 and 3), who reported have frequent pain, said that the pain had an effect on their daily activities. Respondent 1 (female, 55 yrs) described difficulty doing anything when she had the boils: 'With a boil you can't work when you have it. You cannot even touch anything.' All three respondents also reported difficulties with mobility which is the domain most likely to be affected by pain. This relationship is explored further in Chapter 6.

Respondent 2 (male, 65 yrs) described the difficulty of doing anything when one has pain, although he did not have frequent pain, only occasional pain: 'When these pains arrive, I can't do my daily activities …activities using my hands, because I have worked for years using my hands'.

In conclusion, the pain question performs reasonably well as people understand the notion of pain, but not all made clear reference to frequent pain.

5.10 Fatigue

As for affect and pain, a measure of fatigue was not included in the WG Short Set. Fatigue is also a 'feeling' or symptom of some other underlying cause, rather than an activity in itself as seeing, hearing, walking, self-care and communication.

The questions asked to measure fatigue were as follows:

1. Do you have frequent feelings of being tired?
2. In the past 3 months, how often did you feel tired? Some days, most days, or every day?
3. Thinking about the last time you felt tired, how long did the tiredness last? Some of the day, most of the day, or all of the day?
4. Thinking about the last time you felt tired, how would you describe the level of tiredness? Mild, moderate or severe?
5. Thinking about the last time you felt tired, was the tiredness worse than usual, better than usual, or about the same as usual?

The elaborations provided in this section were limited in part due to respondents' fatigue towards the end of the interview.

5.10.1 Understanding the intent of the questions on fatigue

Four respondents (1, 3, 7 and 10) provided correct interpretations of the fatigue questions, while six failed to provide sufficient narratives to allow me to judge the congruence of their

interpretations. Of the four with congruent interpretations, two reported problems of fatigue (1 and 3) and two reported no problem with fatigue (7 and 10). In total, eight respondents had no problems with fatigue.

Respondent 1 (female, 55 yrs) reported fatigue that she attributed to her illnesses (asthma and high blood pressure). She described it, in the quote below, as strongly related to how much she was doing. If she rested she did not get too tired. She said she could not say how often she felt tired, but when given the response options, was able to give a clear response.

Respondent 1:

I: Do you have frequent feelings of being tired?
R: Yes I do feel tired due to the asthma and high blood but when I'm sitting like now, I'm not tired.
I: How often did you feel tired?
R: Huh, always I feel tired, I will not say how many times.
I: But is it every day, some days or most of the days?
R: I can say some days when I work hard I do get tired but when I don't work hard I'm not getting tired.
I: Think about the last time you were tired, how long was your tiredness? Was it some of the day, most time of the day or the whole day?
R: It didn't take the whole day.
I: Does it take some time of the day?
R: Yes, because I get some rest

Respondent 7 (male, 60 yrs) reported 'never' feeling tired (see quote below), but only after he had clarified the intent of the question. He needed to understand that the question asked about unusual tiredness rather than feeling tired after a hard day's work.

Respondent 7:

I: Have you have frequent feelings of being tired?
R: Feeling tired without walking?
I: Yes.
R: Even sitting like this?
I: Do you always feel tiredness and is it a problem?
R: No, I get tired when I have worked such as ploughing the seeds, that's when I get tired.
I: Is it a normal tiredness or tiredness due to a problem?
R: Is just tiredness after working. I just get tired after working.

5.9.2 Themes from the understanding of fatigue

The three themes emerging from the narratives on fatigue related tiredness and pain, how tiredness is managed through resting and the extent to which fatigue is a problem or not.

a) Tiredness related to pain

Respondent 3 (female, 72 yrs) gave clear responses for this domain (see quote below), but she returned to talking about pain while discussing fatigue, as evidenced in this quote, which I reproduce fully to give the flavour of this relationship between fatigue and pain she described .

Respondent 3:

I: Have you frequent feelings of being tired?
R: Yes, a lot – it's as if you worked the whole day meanwhile you haven't done anything.
I: How many times in the past 3 months did you feel tired? Some days, a lot of days or every day?
R: In the past few months it didn't trouble me that much.
I: Was it a lot of days, some days or every day?
R: It's all the time, I feel really tired. It was as if I couldn't do anything, even washing these clothes.
(laughs)
I: Think of the last time you felt tired, how long did it last? Few hours, half the day or the whole day?
R: It was the whole day - when it starts it lasts the whole day. I sleep with pain, thinking that it will be fine by the time I wake up.
I: Think of the last time you felt tired, how would you describe your tiredness, would you say you was mild, moderate or severe?
R: I would get tired a lot while I did nothing.
I: think of the last time you tired, was it worse than usual, as usual or was it worse than usual?
R: It was worse than usual. I thought I was on my way to heaven this time. [Not sure if she is referring to pain or fatigue or both.]
I: Were you too tired unlike the usual or was it better than the usual?
R: I wasn't better.
I: Was it too much?
R: Yes, like when I went to get my grant it was too painful, I had to be helped to get there. [she has gone back to talking about pain rather than fatigue.]
….
R: When I start thinking, I start the pain again.

While this shift between pain and fatigue may be merely a lapse in concentration and respondent fatigue, it does highlight the close relationship between fatigue and pain. Increased fatigue can exacerbate pain and pain can lead to fatigue.

b) The impact of pain and managing pain

Respondent 1 says she rests often in order to manage her fatigue. In addition, problems with both pain and fatigue can have a significant impact on functioning.

In conclusion, the question on frequent pain seems to be understood correctly and can diffferntiate between pain that is frequent and not frequent. The limited narratives provided by respondents due to being tired after a long interview, limited the potential richness of the analysis.

5.11. Case studies: Respondents 3 and 10

In this section, I present two case studies from the ten respondents to provide a more detailed look at individual patterns of responses. Respondent 3 is a good example of a respondent who struggles with answering survey questions, while respondent 10 is a good example of a survey literate respondent, who is able to understand the need for a clear response through averaging his experiences and mapping them onto the given response options. The quotes are presented in some detail to give the reader a flavour of what happens in a cognitive testing interview.

5.11.1 Respondent 3: female, 72 years old living alone.

Survey questions use set response options and it is important for respondents to choose one as their answer to avoid missing data. Respondent 3 struggled with all the questions. She gave extensive narratives but resisted selecting a response option despite numerous repetitions of these. The two main features of Respondent 3's narratives are, firstly a lack of focus on the question, and, secondly, an inability to average out or sum her experiences in the domain of functioning to map onto the given set of response options. However, these same narratives provided evidence that, for most of

the questions, she did understand the intent of the question. Her problem was not in understanding the question,as much as in selecting the response option. The benefit of doing the cognitive analysis allows us to separate out these two sources of respondent error.

The reasons for Respondent 3's difficulty in using the response options can be explained most likely as a combination of low education, herpoor living conditions (her household was classified as 'low'), and her age (72 years) (Loosveldt 1997; Miller 2003): she has no formal education and lives alone. She was very welcoming when we came to interview her and seemed keen to engage with us. Her manner was one of enjoying a conversation with us rather than a focused question and answer session. When interviewed the previous year as part of the 69 semi-structured interviews (see Chapter 6), she reported a sore and swollen knee, and a sore waist and hips. She said she had been bitten by an insect after which her legs swelled up. When asked if she was disabled, she said yes, because 'I lost my parents. A disabled person is unable to do anything - a crippled one'. She had also lost her husband.

I present extracts from her narratives to highlight her problem. Hearing, cognition and self-care were the only domains which she answered clearly and unambiguously. Her narratives for these questions are not presented below.

Vision: This narrative shows the respondent's inability to sum up or average out her experiences to match with one of the response options. She responds using concrete and discrete examples without giving an overall rating.

I: Do you have difficulty seeing even when wearing glasses?
R: Glasses kill a person's eyesight.
I: Do you have a lot of difficulty, not that much or you cannot see at all? [Interviewer presses her for a response that can be noted down on the questionnaire.]
R: Right now I am able to see a person when they are close by, at times my eye sight goes blank.
I: So which answer would you choose?

R: At times I see, it depends on the week; some weeks I can see perfectly, some weeks I have a lot of difficulty. It's better to be deaf because at least whenever people start running, I will see that there's danger.

Mobility: For this domain, her responses waver between 'no difficulty' and 'some difficulty' at the start, but she contradicts herself in saying she 'cannot walk at all' or has 'a lot of difficulty' at other times. The benefit she derives from her walking stick is obvious in her narrative. She has the least focused narrative when responding to the first question (difficulty walking or climbing stairs), and seems to become more focused in her responses with the later, more specific questions.

I: Do you have difficulty in walking or climbing stairs? You don't have difficulty, you have little difficulty, you have a lot of difficulty, or you can't [walk or climb stairs]at all.
R: Hey sir, there is a bus that stops over there, I don't use it. I'll try to get on it with the first try, then the second try, then the third, only I will notice that I am wasting the driver's time from getting his money and driving off. [describing climbing up the steps into the bus]
I: Does this mean you have difficulty?
R: Yes, at most times - even at taxis they usually help me in.
I: I asked if you have difficulties in using the stairs, do you face those difficulties?
R: Yes, I face those difficulties especially getting on the bus at times. If I don't have a firm grip I will usually fall on my back.
I: Please explain whether it means you face a lot of difficulty, a little difficulty or no difficulty.
R: Yes, I face a little difficulty at times [vague response in relation to later responses]
I: Do you use any help to move around or walking?
R: I don't usually go that far [unclear what she is referring to]
I: And to walk around?

She provided contradictory responses about using her walking stick. She said she does not use it to get to the bottle store, but then said she cannot walk as far as the avocado tree without it – a lesser distance than to the bottle store.

R: When I go to the bottle store, I walk there without any assistance, but it is difficult.
I: So you don't use any stick to help you?
R: When I go that side I don't use anything. I'd rather limp to my destination. But for longer distances, I do use a stick because it takes long to get there.
I: Do you use a stick all the time?
R: I cannot walk without my stick not even to that avocado tree you see right there. It's as if I'll fall without it. [Contradicts comment above about only using stick for long distances.]
I: Do you use anything else to help you to walk, besides the stick?
R: There is nothing better than the stick I'm currently using - without the stick I cannot walk.

She provided good examples of the type of terrain that makes it difficult for her to walk and climb stairs. Long distances are not as problematic as hills or stony, uneven paths.

I: Do you have difficulty walking on a level ground?
R: Where the ground is level I can walk until where the road is. [about 200m]
I: Even without the stick? Do you feel any difficulty or not?
R: It only becomes difficult when I walk in places where it's not levelled; my knee gives me problems, causing me to fall.
….
I: how much difficulty do you have even with your stick?
R: I have a lot of difficulty especially on unlevelled fields or ground.

She also reported 'a lot of difficulty' walking inside her dwelling as it can be slippery:

R: I am afraid because it is very slippery inside the house at times, the stick might make me lose balance. I usually use the stick for balancing.
I: So would you say you have difficulties or cannot walk at all?
R: Hmm, there is a lot of difficulty.

When she was given the example of a soccer field for the question on walking for 500 metres, she responds to the example rather than the ability to walk 500 metres.

I: Do you have difficulty walking on a level ground for 500m? Equal to a soccer ground?
R: I do not attend soccer matches nor walk on soccer grounds, I hardly go anywhere
I: That was just an example. What we mean is do you have difficulty walking the same distance?
R: I don't have a problem where the ground is level, I rest every now and then - I will end up reaching my destination.
I: So there's no difficulty?
R: Not at all.

Communication: Respondent 3 misinterpreted the communication question intent. She interpreted communication as being unburdening oneself rather than being merely about using language for communication, as shown in her narrative. Her narrative concludes with a correct response of 'no difficulty' but this required a number of repeated attempts on my part to clarify the question.

I: 'Using your usual language, do you have difficulty communicating, for example understanding others or being understood?
R: Who will understand me?
I: For instance when talking to me, can you or will you be able to explain to me anything in a way for me to understand, or do you have difficulties in doing so?

R: Yes, when I meet a person I am able to express myself and let them know what troubles my life.
I: Do you explain it to them so that they'll understand? Can you say that you have no difficulty in being understood or understanding or do you have difficulties?
R: When you are troubled you should be able to express yourself to your neighbour and let them know what troubles you.
I: In a way they'll understand you?
R: Yes
I: This means that you have no problem in understanding or being understood?
R: Yes, it's as if I have taken a load off myself.
D: Can I please repeat the question? When using your mother tongue are you able to understand or are you understood when using it?
R: I will not change my mother tongue to suit others, this is my mother tongue and thankful of my mother tongue and thankful for it. I grew up speaking it and found people speaking it.
D: So you don't have any difficulties being understood?
R: Not at all.
D: Do people have difficulties understanding you when you speak?
R: Not at all.

Affect - Anxiety: The narrative for the question on anxiety is another example of Respondent 3's inability to average out her experiences into one response.

I: How often are you worried, nervous or anxious - has it happened daily, weekly, monthly or a few times a year or it never happens?
R: That happens a lot, because of the thieves, you'll hear that they broke into someone's house and stole. So your heart always pains.
I: Does it happen everyday, weekly, monthly or a few times a year?
R: If I worry this week, the following week I don't worry anymore, but in the following week I hear of a break-in, my heart starts paining again.

She provided clear examples of the cause of her anxiety and worry:

I: Have you ever been attacked by thugs
R: They always break in here – when I'm asleep.
I: Does it happen often?
R: No, it happens usually when they know that I came from the field [when she has finished ploughing]. They know that I don't have a child here. So it's better - they come and steal.

Affect - Depression: She seemed to interpretthe question on depression correctly, but avoids using response options. She was getting tired of the interview.

I: How often do you have depression? Would it be everyday, weekly, monthly or a few days within a year or you've never been depressed?
R: Mmm, I do get depressed

I: How often does it happen?
R: When it starts I'll feel my body getting tired and dizzy
I: I want to know how often it happens.
R: It happens this week, it won't come back the next. It will happen the week after and then stop.
I: It happens this week and skips another and starts again?
R: Yes
I: Do you use any medication when you are depressed?
R: I don't use any.
I: Think of the last time you were depressed, how was it? Was it a little, a lot or too much?
R: It would be too much
I: Was it too much?
R: Yes

Pain: She reported having frequent pain for the first question, but failed to provide clear responses for the later questions. Her narratives were not focused on the question, although they were about pain. She failed to use the response options provided.

I: Do you have frequent pain?
R: Yes
I: Do you use any medication for the pains you get?
R: No, I last went to the clinic when I broke my arm.
I: In the past three months how many times did you have or feel pain? Some days, most days, every day?
R: What happens is that, it feels as though someone is [unintelligible] and then it feels like I have a brick on my head.
I: How often would you say it is, though?
R: When it starts, it can last a week.
I: Think of the last time you felt pain, how long did you it last? A few hours a day, half the day or whole day?
R: When it starts it is from the morning till night.
I: Think again about the last time you were in pain, was it a little pain or a lot or between?
R: I have pains where I end up sleeping on the floor. If I do, no one will help me work.
I: So would you say it's a little pain or a lot or in between a little and a lot?
R: If I'm sick I'll tell my neighbour. So that if no one sees me they must let each other know and look for me and check if I'm fine.
I: We want to understand that when you in pain is it a lot, little or in between?
R: I am able to work. If I don't have anyone to help me because I have no one who will work if I just lie around?
I: So you are forcing yourself? It's too painful?
R: Yes

I: Think of the last time you were in pain, was it worse than usual or better than usual or it was like usual?
R: Sometimes it's usual, sometimes it's unusual.
I: How would you explain the pain?
R: I would tell someone, just in case they don't see me they'll know that I said I was in a lot of pain.

Her narratives describe an intermittent pain, which may have complicated her ability to average out her experiences to map onto the given response options.

I: Please explain how the pain feels?
R: There are times where I have pain right here, sometimes I get headaches and sometimes my tummy gets sore and from there to my waist.
I: The pain that you feel is it a steady pain, sharp pain or does it come and go?
R: It comes and goes.

Fatigue: She provided a good description, despite showing some overlap between pain and fatigue towards the end. She made a reference to emotional pain. Her narratives are similar to those for pain, where she is able to respond to the yes/no structure of the first question but struggles to respond on later questions that use more than two response options.

I: Have you frequent feelings of being tired?
R: Yes, a lot – it's as if you worked the whole day meanwhile you haven't done anything.
I: How many times in the past 3 months did you feel tired? Some days, a lot of days or every day?
R: In the past few months it didn't trouble me that much.
I: Was it a lot of days, some days or every day?
R: It's all the time, I feel really tired. It was as if I couldn't do anything, even washing these clothes.
(laughs)
I: Think of the last time you felt tired, how long did it last? Few hours, half the day or the whole day?
R: It was the whole day - when it starts it lasts the whole day. I sleep with pain, thinking that it will be fine by the time I wake up.
I: Think of the last time you felt tired, how would you describe your tiredness, would you say you was mild, moderate or severe?
R: I would get tired a lot while I did nothing.

It is not clear in her narrative whether she is referring to fatigue, pain or a combination of both, and her last remark for this domain suggests that she is thinking about emotional pain as well. The relevant quote is provided in the analysis of the fatigue domain questions before the cases tudy.

5.11.2 Respondent 10: Male, 54 years old, living with his wife and children and working as a carpenter.

This respondent welcomed us for the interview and was alert and engaged in the whole process. He is a member of the local school's governing board and seems to be involved in a range of family and community activities. He is a devout Christian and made references to reading the bible and living a good life as examples of how he lives his life. He has limited education but has a level of literacy that does allow him to read the bible.

His narratives are much more focused and unambiguous than those provided by Respondent 3 described above.

Vision: His difficulty reading small print in poor light does not change his overall rating of 'no difficulty' in seeing.

> I: Do you have difficulty seeing even when wearing glasses?
> R: I don't have difficulty seeing, but at night I can't read the bible or reading small letters, but during the day I have no difficulty. This was affected by watching television.
> When prompted for use of response options:
> I: According to the answer you gave would you say no difficulty or some difficulty?
> R: I feel I have no difficulty because the time I work is during the day and seeing during the night I have no difficulty [other than reading small print].

Hearing: He provided a good overall rating but qualified it by describing a unilateral hearing problem.

> I: Do you have difficulty hearing even when wearing a hearing aid?
> R: I have no difficulty but I have one ear that is not [hearing] properly but the other one functions well. I can feel that when I close the other one.

The cause of his hearing problem was described earlier in the section on Hearing, and he reported no difficulty hearing in noise.

Mobility: He had a good understanding of the distance references.

I: Do you have difficulty walking or climbing steps? When we say steps we mean steps like the one in town that you climb to [get to] the next building.
R: I have no difficulty
I: Are you thinking about walking and climbing when you say you don't have difficulty?
R: Yes
When asked about walking 100m:
R: I have no difficulty
I: Do you understand the distance of 100 meters?
R: Yes I do understand. 100 meters is like that way that goes down there - it's 100 meters. [Shows a distance of approximately 100m].
When asked about walking 500m:
R: I have no difficulty walking half a kilometre. [Spontaneously used 'half km' reference]]
I: How far can you walk?
R: I walk 8 to 10 kilometres
When asked about climbing steps or a small hill:
R: No difficulty

Cognition: He provided clear examples of what his problem in remembering and concentrating were, such as forgetting where he had placed his jacket. His reference to 'it's not that difficult but it is difficulty' shows that he sees these as part of growing old rather than a more significant difficulty.

I: Do you have difficulty remembering or concentrating to do something?
R: I have a problem of remembering. With remembering… if I can get in to the car holding something, if I think of something else, I can forget [the object in the car] there.
When pushed to give a specific response based on the response options:
I: In that one of remembering something - do you have lot of difficulty or do you have some difficulty?
R: These things - it's not that difficult but it is difficulty.
I: So you have some difficulty?
R: Maybe as I keep growing older, but now it's not that bad.
Example of forgetting something:
R: like when I'm having something on my hand when I put it down it happens that I forget it for a long time; like when I'm wearing a blazer - when I take it off er… it happens that when I want to go somewhere I go without the blazer. [i.e. I forget it]
When asked specifically about concentrating:
I: So that other aspect of concentrating, would you have difficulty with it?
R: If I like doing something I have no difficulty doing it. If I want to do something I just do it at that time.
When asked about forgetting important things:

R: It is not that much of a difficulty but the only problem is that of forgetting things, but remembering things is not a lot of problem and forgetting things does not happen all the time, it just happen sometimes. [Confusion between forgetting where he placed things vs remembering names of people or objects.]
<u>When asked about level of difficulty last time he forgot</u>:
R: When you forget something it ends up being lost forever, so that means it's a difficulty.
I: Is it some difficulty or a lot of difficulty?
R: I don't have a lot of difficulty.
<u>When asked about concentrating for 10 minutes</u>:
R: When I want to do something I have no difficulty, if I want to do something now I can do it without spending more than 3 minutes. [interpretation of 'doing' rather than 'concentrating on something']
….
R: I have no difficulty doing something.

The short narratives and lack of problems he reported forself-care, communication, anxiety , depression, pain and fatigue reflect a good ability to process the questions and map his experiences onto the given responses. In his narrative about depression, he described this as being about losing a relative initially but expands this to include tension in the home and financial worries as reasons for feeling depressed and 'not being well'.

I: How often do you feel depressed? Is it daily, weekly, monthly, a few times in a year or never felt depressed?
R: I never had depression because depression comes when you have lost some relatives and it has never happened to me.
….
I: Do you have it [depression] sometimes?
R: Yes it might happen there and then but I learnt a lot about it on the verse that says "be glad in the Lord always" so when I come across something I just ignore it
I: Er… What is depression?
R: A depression is something that… depression is just an English word which means something that makes you feel depressed and not being well; like when a relative has passed away or you are not understanding each other with the wife or children, when they do silly things. All of these can make you feel depressed. Or maybe your financial status. When you put all your mind to it [focus on it], this can make you feel depressed as well.
I: Do you use or take medication for depression?
R: No.

5.12 Common themes across the ten domains

This section sums up the major strengths and weaknesses of the ten domain questions and rates the performance of the individual domain measures as reflected in the correctness of the interpretation of the question intent and ability to average out experiences and map these onto the given responses options.

The focus for this thesis is always on the first question of the domain. The first question introduces the domain and, if a person misinterprets it, this may determine the interpretation of the remaining (extended) questions or determine a skip pattern that may be incorrect for that respondent. For example, reporting 'a lot of difficulty' remembering or concentrating because of 'emotional remembering' (a misinterpretation), leads to other questions in that domain being asked. The extended questions would be skipped if the person reports 'no difficulty' on the first question.

5.12.1 Use of response options

In a survey context, a respondent must choose one response from a predetermined list of responses. If a respondent does not use the response options or provides a long explanation without providing a specific response, the data will be reported as missing or the interviewer must make a judgement as to the correct response, neither of which are conducive to good data collection.

A number of respondents struggled to use the question response sets. The extreme case is that of Respondent 3 whose narratives are analyzed above in detail.

Table 6 provides a breakdown of the respondents who had difficulty using the response options for the different domains. This is compared to the respondents who misinterpreted the question intent.

Table 6: Respondents who had problems in using response options and who showed 'misinterpretations' for the ten domains

Domain	Number of Respondents with problem using response options (Respondent number in brackets)	Number of Respondents with misinterpretations of question intent (Respondent number in brackets)
1. Vision	2 (3, 9)	None
2. Hearing	None	None
3. Mobility	2 (3, 7)	None (few problems were about references to distances in later questions, and not misinterpretations of the first question)
4. Cognition	5 (1, 3, 7, 8, 10)	6 incorrect (1, 3, 4,7, 8, 9)
5. Communication	None	1 (3)
6. Self-care /Upper body mobility	None	None
7. Anxiety	3 (3, 5, 7)	None (differences occur on causal pathways)[42]
8. Depression	3 (3, 4, 7)	4 (1, 3, 4, 7)
9. Pain	1 (3)	Not determined because of insufficient narratives
10. Fatigue	1 (3)	Not determined because of insufficient narratives

The domain of cognition yielded the most number of respondents with problems – five out of the ten were unable to provide a clear response. This was followed by the domains of anxiety and depression. Respondent 5 for anxiety and respondent 7 for depression raised the point that these are not measurable states of being and, hence, they were not able to give a clear response option, which assumes different levels, which assumes the possibility of different levels of anxiety and depression.

For the domain of cognition, the major theme was the misinterpretation of remembering as 'emotional remembering' or 'ruminating' rather than recalling names and important things.

[42] Another way to analyse the interpretations of Anxiety is to count all as incorrect if the assumption is made that only the internally triggered or endogenous causal pathway is considered the correct interpretation.

Remembering, as intended by the question, comprises an action of remembering, while ruminating is about how one feels. Given the difficulty in responding about levels of anxiety and depression, a similar problem may have occurred for 'ruminating' resulting in problems applying the response options. This is merely a hypothesis as to the possible reason and would need further cognitive testing of these measures to determine the correctness of this hypothesis.

5.12.2 Misinterpretations

Misinterpretations occur when the interpretation by the respondent is not congruent or concordant with that of the question intent. As discussed at the start of this chapter, they are important to note as they give insight into how people have understood the intent of the question. They inform the data users on question revisions that are required and possible sources of response errors to consider in the analysis. Only those interpretations that are clear deviations from the intent (as set out in Table 5 above) are discussed here.

Misinterpretations that I discuss relate to survey questions to ensure transparency in the disability statistics generated. This is the focus of my thesis. However, these misinterpretations also provide a useful perspective on how people view their lives, their health and functioning. Some of the frustrations expressed by respondents when pushed to provide a 'survey' response and the sometimes tangential nature of some of the narratives gives insight into these views. They remind us that survey questions only provide a part of the information and can be restrictive in their scope. More qualitative and in-depth analyses provide complementary information. My task in this thesis is to make sure the survey information is good and valid. If all or most respondents showed misinterpretations on all or most of the questions asked, I would have to conclude that the questions are not appropriate and do not reflect people's lives. However, this is not the case for the WG Extended Set questions.

In Table 6 above,I present the number of respondents with incorrect interpretations for each domain. The misinterpretations were most common in cognition, and were the same for all respondents: 'emotional remembering' or 'ruminating'. This suggests that the Shangaan translation of the question should be revised, for example, by including some examples to direct the respondent to the correct interpretation. Examples could include remembering names, important things such as appointments, or taking medication.

For the domain of communication, Respondent 3 interpreted this question as unburdening her emotions rather than using expressive and receptive language. A common interpretation for anxiety was in relation to unmet needs, reflecting an external cause for the anxiety, and not necessarily a clinical anxiety. The difference is in the hypothesised causal pathway – anxiety causing difficulty in functioning versus difficulty in functioning causing anxiety. This is discussed in more detail in the next chapter.

These misinterpretations of the questions on remembering and communication, and reported causal pathways of anxiety and depression, together depict a picture of high levels of negative emotions in the ten respondents. The relevance for question evaluation is twofold. In the first instance, the respondents' narratives point to the need for some revision in translation at the question level. Secondly, the analysis informs the data users about areas to consider when interpreting the results obtained from using these questions, within the context of how they were interpreted.

Some other minor misinterpretations related to distance references (walking 100m or 500m) and size references (2 litre jug of water) that were not clearly understood in the initial or main questions posed. Respondents reflected in their narratives that they were generally thinking of much larger distances or size of water containers. This led to a few initial incorrect responses until a concrete example was given (e.g. a 2 litre coke bottle). These misinterpretations are closely related to the conditions of life in the area where people walk long distances and carry large containers of water

when fetching water from the communal tap, and are important to understand when comparing statistics from rural, low resource areas (such as used in this thesis) and urban, highly resourced areas where people do not walk much or do not have to lift heavy containers of water. Difficulties reported in each of these areas may not be measuring the same level of functioning if these references are not clearly specified and understood. This is particularly relevant for the first questions that make up the WG short Set of questions where statistics are obtained from those single questions, without the clarificatory role of the extended set of questions. This was noted for the domains of mobility, specifically, where the initial question has no distance reference and may, therefore, be interpreted differently by respondents living in different geographical and social contexts.

The remaining domains had no misinterpretations, suggesting that those measures are good measures of the intended domain of functioning.

5.12.3 Feeling domains[43] versusActivity domains[44]

As discussed above, respondents talked about the inability to measure their feelings of anxiety and depression using the discrete response options. This was the case for two respondents. A 'yes/no' response may have facilitated giving a response. Yes/no responses are suitable for identifying the presence of a phenomenon (e.g. depression or anxiety) without specifying the degree of difficulty. In other words, one has or does not have anxiety and depression. The other domains are more physical in nature and are more amenable to being measured in a graded rather than yes/no approach, allowing the use of the four graded response options denoting levels of severity.

[43]Anxiety, depression, pain and fatigue.

[44]Vision, hearing, mobility, cognition, communication and selfcare.

5.12.4 Difficulty being part of normal life

The domains of anxiety and depression and, to some extent fatigue, were seen as features of normal life and experienced by all. This makes the division between what is pathological or diagnosable depression or anxiety versus 'normal part of life' difficult using a single question. Most of the respondents reported 'never' having a problem or problems only 'a few times a year', with no significant impact on their daily life. The rationale used by the WG for using extended questions for these domains was precisely to identity anxiety that occurs frequently, is of long duration and high intensity; in other words, anxiety that is more likely to be a significant problem and probably clinically diagnosable. The results of the UNESCAP/WG testing of these questions (UNESCAP 2010) showed that, by using the extended questions for these domains,the analysis was able to group people into those with mild or no problems through to those with severe problems that have a significant impact on their daily lives. The narratives provided by the ten respondents reflect mild to no problems with anxiety and depression – a 'normal part of life' and a reaction to living in a context of low resources with the related stress and insecurity as described by various authors discussed above (Lund et al. 2011; Moussavi et al. 2007; Aidoo & Harpham 2001; Patel & Kleinman 2003; Patel et al. 2001; Havenaar et al. 2008).

5.12.5 Overall performance of questions

The results presented in Table6 show that, of the ten domains tested, six are understood and interpreted consistently and correctly (by all or almost all respondents) as per the intended meaning of the question (see Table5 above). These domains are: vision, hearing, mobility, communication, self-careand upper body mobility, and anxiety. We can thus be relatively sure that when we ask these questions we are measuring what was intended – functional status in these domains.

The remaining four domains (cognition, depression, pain and fatigue), show poor performance or a performance that warrants further investigation before we can be sure of the question performance and how to interpret the statistics. This is discussed further in Chapter 7.

Answers to the questions posed at the start of this chapter can now be provided. Firstly, the different domains are interpreted with different degrees of correctness. The more traditional disability domains are the least likely to be misinterpreted, and the domains that reflect more states of being than activities, are more likely to be misinterpreted.

Secondly, the patterns of errors produced by misinterpretations have important implications for the validity of the measures. If these misinterpretations, such as emotional remembering and anxiety related to external factors, are not taken into account, incorrect inferences will be made as to the meaning of the disability statistics derived. The remedy is based on the reasons for the misinterpretations. In the case of translation problems, as noted in the Shangaan translation of remembering, the question needs revision to ensure that the correct interpretation is elicited. In the case of ambiguous interpretations that suggest contextual rather than health related causes of the difficulty, as is the case in relation to levels and causes of anxiety, the remedy, for the survey methodologist, is to ask questions specifically on the respondent's reason for their answer. This would generate a series of probe questions to 'check out' what interpretation the respondent has applied. All 'incorrect' interpretations can then be filtered out at the analysis stage. This approach was used by the WG/UNESCAP cognitive and field testing of the WG Extended Set of questions, as discussed above, and found to be very effective in separating milder and less significant difficulties from more severe and significant ones (UNESCAP 2010).

5.13 Chapter conclusion

In this chapter, I sought to evaluate the WG Extended Set questions with respondents from a rural area of South Africa. The ten respondents were older than 50 years, except for one respondent, all had limited education and lived in a context of hardship. Their responses and related explanatory narratives show that the questions are good questions as they elicit consistent and congruent interpretations for all domains except cognition. The role of context, as described in Chapter 3 and at various points in this chapter, is important to understand people's references and frame of mind

when giving responses about walking, lifting containers of water and reporting difficulties with the feeling domains. The next chapter analyses this role in more detail.

This chapter also illustrates how the Cognitive Assessment for survey Methodology (CASM) approach can be used to evaluate question understanding and interpretation and adds to the growing body of work in this area for surveys generally and disability measurement more specifically.

Chapter 6

Functional profiles and life context factors

In the preceding two chapters, I explored two potential sources of respondent error for disability questions – the wording and the process of interpreting the whole question. In this chapter, I consider a third aspect – the overall life context of the person. How are factors such as available resources, social networks, life satisfaction, and religious beliefs associated with responses people give to the questions measuring disability?

This chapter provides evidence for the third objective of this thesis, which explores the relationship between people's responses and their overall life context. This is the contextual level of analysis. In order to achieve this, firstly, I develop profiles of severity and type of difficulty, and, secondly, explore the association between these profiles and a number of life context factors. The results provide some suggestions on the possible role of these life context factors in determining responses to questions. The specific questions I ask include: a) What typical response profiles, if any, were found?; b) What typical life context factorswere described by respondents?; and c) What is the association between response profiles on the disability questions and the life factors? The life contexts and functioning profiles are those of respondents living in Agincourt.

In summary, the map of this chapter is as follows:

- The SAGE questions were used for calculating total functioning scores (TFS) as described in Chapter 3. The questions selected from the SAGE Short version were those for basic activity and feeling domains (Appendix 6a and b).
- The TFS were analysed by severity of difficulties and the domain contributing most to that severity, or type of difficulty. These were described as profiles of functioning. This analysis provided the basis for determining which profiles were reported more commonly and with what level of severity (Sections 6.1 and Section 6.2).

- A comparison was made of the difficulties reported by the SAGE and the WG Short Set questions for the same respondent to determine whether the differences may shape conclusions drawn from the TFS (Section 6.3).
- The profiles of functioning were analysed in relation to various life context factors to determine if any associations could be gleaned between these life factors and the severity and type of profiles identified in Sections 6.1 and 6.2 (Section 6.4).
- A more detailed examination was undertaken to determine whether the health conditions reported by respondents reflected the type of functional difficulties they reported on the SAGE questions. The findings of this analysis are reported as part of Section 6.4.1 on life factors.

The use of profiles is a descriptive technique that provides a typology of different and typical response types – a system of classification (Grix 2004). These typologies are used to organise the data in a way that leads to further analyses and knowledge production. The functioning profiles are, furthermore, a good strategy to use in combination with summary scores. The single number or summary score (a useful tool in analysing large national and international data sets) masks important differences in functioning and experiences, where two people with the same score may have very different types of difficulties - one with cognitive difficulties and the other with mobility difficulties, for example. The use of profiles of severity and domain types gives a more nuanced description.

The data used for this analysis are the 69 semi-structured interviews carried out in the five villages in Agincourt in May/June 2008. As I explored in Chapter3, the main difference between the WG and SAGE questions is the use of five response scale for the SAGE questions, and four for the WG questions. The response options for the SAGE questions are: 'no difficulty', 'mild difficulty', 'moderate difficulty', 'severe difficulty' and 'extreme difficulty'. The response options for the WG questions are: 'no difficulty', 'some difficulty', 'a lot of difficulty' and 'unable to do/cannot do'.

6.1 Total functioning scores (TFS) and severity of functioning profiles

The SAGE questions were categorized into the different domains (sensory, mobility, cognition, communication, self-care, affect, sleep and pain) as described in Chapter3. Total domain scores were calculated with each domain, contributing 20 points[45] on a scale of 0 – 140, with an increasing score indicating increasing difficulty. The score out of 140 is the total functioning score (TFS). The different domains comprised different numbers of questions – some had only one question while others had up to four questions, as I explained in Chapter 3 and in Appendices 6a and 6b. .

The resulting scores are presented in Figure8 ordered according to individual respondent interview number – one number represents one respondent, from respondent 1 through to respondent 69.

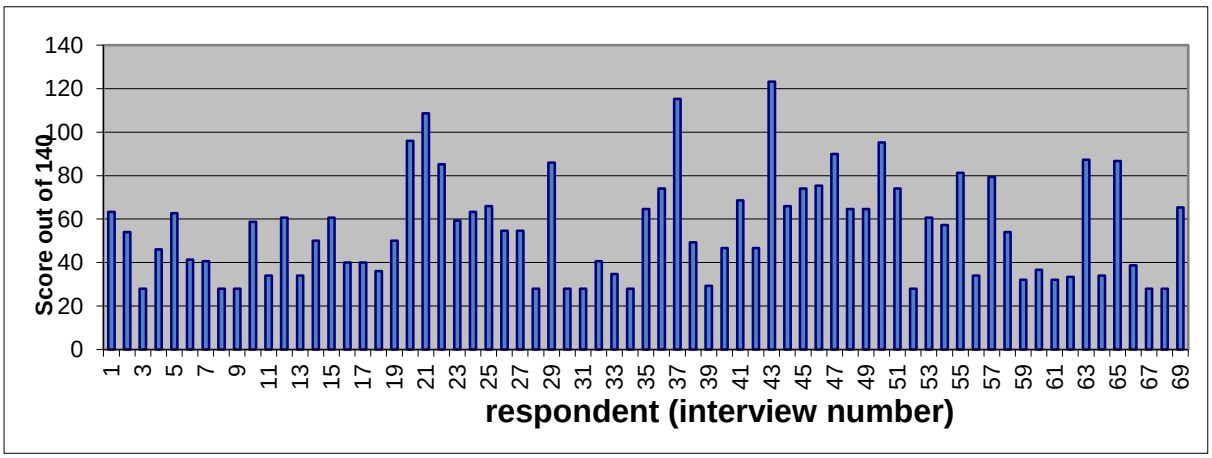


Figure 8: Total scores (out of 140) for SAGE domains from 69 interviewees[46]

The total functioning scores werecategorized in multiples of 10 from 40 upwards. A respondent with no difficulties on any domains will score between 0 and 39, giving the first category of 0 – 39 of 'no difficulty'. The other categorizations are provided in Appendix 6b. Figure 9 presents the number of

[45] To recap briefly, the sum of the scores for all the questions subsumed into one domain was multiplied by a multiplier to get a score out of 20. This allowed me to compare domains in relation to their score out of 20.

[46]Respondent number corresponds to their interview number for ease of reference throughout the chapter.

respondents in each category. The majority of respondents reported lower levels of difficulty. This is not an indication of prevalence as the sample was selected purposively, as described in Chapter 3.

The majority of the respondents had no difficulties or minimal difficulties, as reflected in the score of 0-39. Only three respondents had scores of 100 or more.

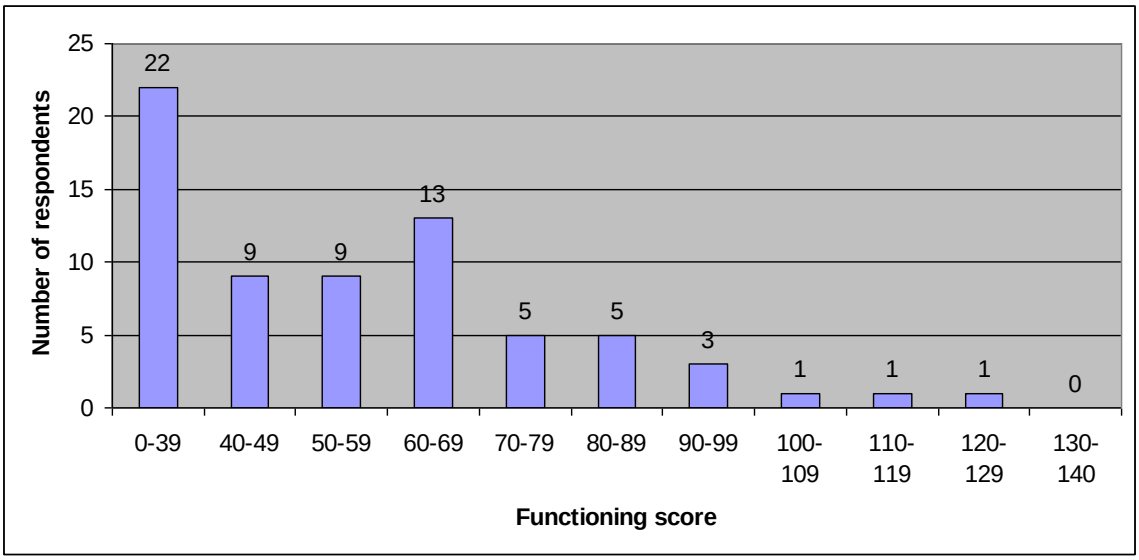


Figure 9: Categorization of total functioning scores (N=69; SAGE domains only)

The categories were reviewed and a cutoff point selected to differentiate between different levels of severity. While different cutoff points could be selected, I decided to use a simple approach of allocating the same interval between the different categories – 20 points on the TFS scale. Figure10 presents theseverity scorescategorized into five levels of severity: no difficulty, mild difficulty, moderate difficulty; severe difficulty and extreme difficulty. This technical, and somewhat arbitrary, setting of the cutoff points results in a reasonable progression from one category to another. The majority of the respondents are in the 'no difficulty' or 'mild difficulty' categories, and the least are in the 'severe' and 'extreme' difficulty categories. A slightly adjusted cutoff between the 'moderate' and 'severe' categories may have given a more consistent decrease in the number of respondents in each category. However, the aim of this categorization was to facilitate further analysis, rather than develop a fully defensible set of cutoff points.

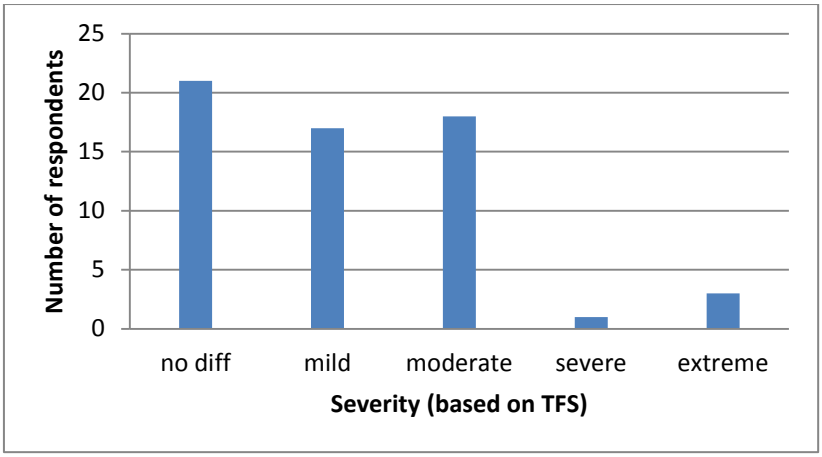


Figure 10: Categorization of TFS into 5 severity categories (SAGE domains only)

Five respondents had TFS which were borderline, for example, 39.75 or 59.55. These were categorized into the higher category in all five cases. The categorization of the TFS was as follows:

- No difficulty – TFS = 0 - 39
- Mild difficulty – TFS = 40 - 59
- Moderate difficulty – TFS = 60 - 79
- Severe difficulty – TFS = 80 - 99
- Extreme difficulty/cannot do – TFS = 100+

Of the 22 respondents with 'no difficulty', one respondent had a score that fell within this category (TFS = 33.33) but who also reported 'extreme difficulty' with pain, and 'mild difficulty' in mobility and self-care. This respondent had missing responses for the other domains which, thus, contributed '0' to the TFS resulting in a low score. This was the only respondent where this happened and does suggest that missing data needs to be considered carefully in applying any algorithms using the TFSor similar summary score. While this respondent would be omitted from analyses of survey data, I retained the respondent's information for this descriptive analysis.

6.2 Type of difficulty profiles

6.2.1 Overview of domains

As I set out in Chapter 3 and Appendix 6a, each total domain score contributes equally to the total functioning score (even if they have different numbers of questions contributing to the domain score). Thus the domain contributing the highest score (out of 20) to the TFS for each respondent was noted as the 'main' domainof difficulty and this domain determined the type of difficulty category for each respondent. This was done only for those respondents with difficulties (i.e. TFS => 40). There were 50 respondents with difficulties. Figure 11 sets out the results of this analysis. This profiling highlights what the respondent reports as their main difficulty.

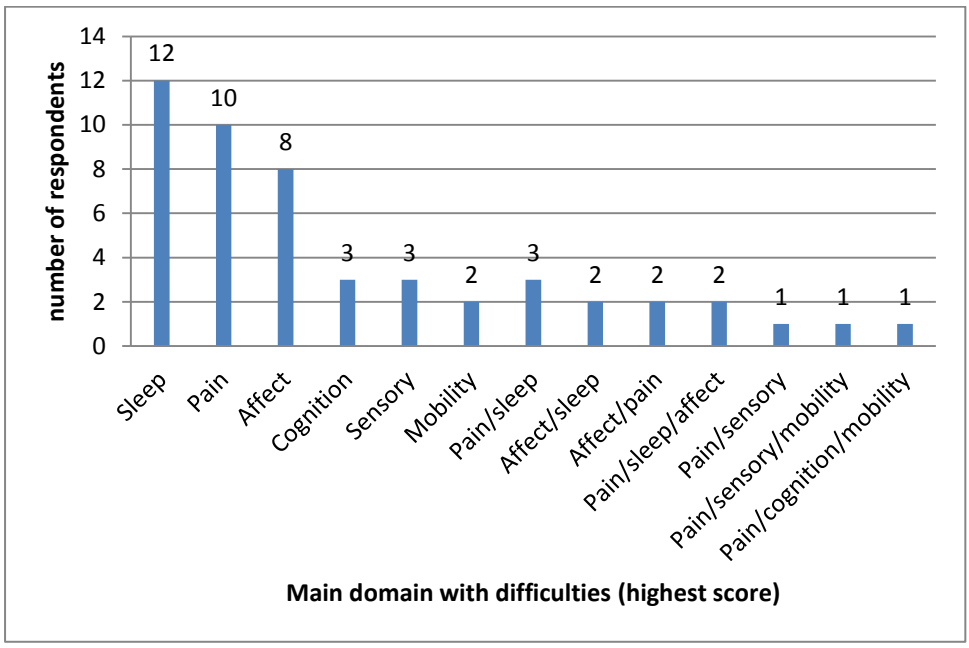


Figure 11: Number of respondents with different types of main difficulties (N=50)

The approach used was as follows:

1. the domain with the highest score was set as the main domain contributing to the TFS (single domain profile).

2. if more than one domain had the same score they were combined into one group (multiple domain group)

The severity profiles presented in Figure11 only reflect the highest scoring single or multiple domains of the profile (domain with the most severe difficulty). In addition each domain that contributed a score equal to or greater than 10 were included in the profile and noted as second, third or fourth highest scoring domains in the profile accordingly (but not included in Figure 11).

By far the most common single domains determining severity (TFS) were sleep, pain and affect, in that order. These are not the 'traditional' domains of disability, such as sensory, physical, psychological or intellectual functioning. Furthermore, these three domains are reported with difficulties in combinationwith other domains. For example, pain is associated as one of a group of domains or the single domain determining the TFS severity for 20 out of the 50 respondents with difficulties. Pain in addition was most commonly associated with affect and sleep. A greater number of respondents reported being in pain, feeling anxious or depressed, and having problems with sleep than they reported difficulties with seeing, hearing, mobility, communication, self-care and/or cognition.

Table7: Number of respondents with profiles including pain, affect or sleep (N = 50)

Domain Type	**Number of profiles with these as a single main domain or in combination with other main domains**
Pain	20
Sleep	19
Affect	14
Pain + affect	2
Pain + sleep	3
Affect + sleep	2
Pain + affect + sleep	2

Of the 50 respondents, only eight had no problems with pain, affect or sleep, as presented in Table 7. Sensory (three respondents), mobility (two respondents) and cognition (three respondents) were the main domains with difficulties reported by these latter respondents. These figures are much lower than the number of respondents reporting pain, affect and sleep as their main difficulty. Difficulties in the domains of self-care and communication are absent as a main profile domain. Self-care and communication difficulties are typically reported less frequently than other difficulties (Schneider et al. 2009), and tend to emerge only when other more basic domains of functioning display significant difficulties, such as vision and mobility difficulties (Cambois et al. 2005).

6.2.2 Self care and severity of TFS

Further analysis shows that self-care difficulties werereported only by respondents who had 'extreme' or 'severe' TFS. The three respondents with extreme difficulty (Rs 21, 37 and 43) all had a TFS greater than 100 and all three reported having self-care difficulties. Respondent 21 was a 36 year old female who reported swollen legs and difficulty moving her hips and legs. Respondent 37 was a 51 year female who had suffered a stroke and a wheelchair user. Respondent 43 was a 62 year male who was blind and had diabetes and high blood pressure. They also reported having difficulties in the cognition, sleep, pain, mobility, affect and, for two respondents, sensory domains. Two reported themselves to be non-disabled and only one said that she was disabled (R21), because 'I cannot do anything on my own; A disabled person cannot walk, work or feed themselves.' Respondents 37 and 43 explained why they are not disabled : 'No, I was born normal. It happened as life goes on' (R37) and 'I cannot mix this with disabilities because it is something which I didn't ask for - God just gives it to you.' (R43).

Two respondents had severe TFS (R20 and R22). Respondent 20 was a 77 year old female who reported that her muscles stopped functioning normally and her legs were covered in sores. She complained of pain in her whole body. . Respondent 22 was a 69 year old male who had had a stroke and was bedridden. We interviewed him while he was lying on a thin mat on the floor. He was

emotionally labile but was able to respond to the questions. Both respondents reported self-care difficulties in addition to difficulties in four or five other domains, and being disabled:'A disabled person is someone who is unable to do things on his own.' (R20) and 'I cannot do things on my own. A disabled person does not know anything.' (R22). Respondent 22 reported the most difficulty for pain, cognition and mobility, followed by affect and self-care.

The one person (R46) who reported self-care difficulties with a TFS of moderate severity, reported additional difficulties in pain, affect and cognition. She was a 59 year old female who reported pain in her legs and hips and high blood pressure for which she takes medication. She did not see herself as disabled:'A disabled person does not speak, walk, talk good or is dumb, and even does not see. I do have all these qualities.' (R46).

In conclusion, the type of profile is dominated by three domains – pain, sleep and affect. The lack of congruence of these with the typical or traditional notions of what disability is (difficulties in seeing, hearing, talking, walking, thinking or self-care or 'Deaf, blind, crippled or mentally retarded') raises interesting points about what these disability questions are in fact measuring that is different to the traditional 'disability' focused questions. Chapters 4 and 5 already provide some indications as to the underlying factors that shape people's responses to the questions. The description and analysis of the life context factors provide a further window on what these questions may be measuring.

6.3 Comparison of WG and SAGE domains of difficulty

The WG and SAGE sets differed in the number of response options, and the number of questions per domain. The WG Short Set used four response options and asked one question per domain, and did not include the domains of affect, pain and fatigue. The SAGE used five response options and included more than one question in most domains, and included the domains of affect, pain and sleep. Since the main domains of difficulty were those of pain, affect and sleep, as presented in the preceding discussion, it is interesting to see what domains are reported as most difficult on the WG

Short Set compared to those reported as difficult on the SAGE questions. I compared the main domains with difficulty in the WG Short Set (i.e. the domain question which had a score close or equal to 4) and SAGE (i.e. the domain score closest or equal to a score of 20).The purpose of this analysis was to explore what happens to a respondent's profile on each set of questions.

In Table 8, I present a summary of the major trends in the similarities and differences between the WG Short Set and SAGE question profiles. This table wascompiled as follows:

- The allocation of 'same' or 'different' status was determined by the main domain only.
- Each respondent was coded only once as 'same' or 'different', but could be coded a number of times for the subcategories based on both the main domain and the other domains with a lesser degree of difficulty.
- If a respondent reported mobility difficulties in the WG Short Set and difficulty with Pain in the SAGE, he or she was coded in the 'mobility and pain' sub-categories. This was applied to both 'Same' and 'Different' profiles. These respondents were coded in the 'same' category if they reported difficulties in pain on the SAGE and in mobility on both sets. If mobility was reported as difficult on the WG Short Set and not on the SAGE, but pain was reported as difficult on the SAGE, these respondents were counted in the 'different' category.
- The same approach was used for self-care and pain, and remembering and affect difficulties.

Overall, 37 respondents had the same main domain for the WG Short Set and SAGE questions, and 32 had a different one. Having the same main domain on both sets of questions means that the same functional difficulties are identified on both sets of questions for one person. If they are different, the person is described as having different functional difficulties on the two sets of measures.

Table 8: Comparison of Main difficulty domains for WG SHORT SET and SAGE questions (N=69)

Outcome of comparison between WG Short Set and SAGE	Number of respondents
SAME profile on both sets	**37**
No difficulty on both	13
Minimal difficulty on both	1
Same but with additional SAGE domains	Pain**= 4 Sleep= 12 Affect= 9
WG: Mobility as the main domain SAGE: Pain as the main domain with mobility difficulty	20
WG: Remembering as the main domain SAGE: Affectas the main domain with remembering difficulty	2
DIFFERENT	**32**
WG: Remembering as main domain SAGE: Affect as main domain and no remembering difficulty	6
Additional SAGE domains and no WG Short Set domains	Pain**=5 Sleep=15 Affect=10
Additional WG domain and no SAGE domains	Hearing = 3
WG: Mobility as main domain SAGE: Pain as main domain and no mobility difficulty	11
WG:Self-care as main domain SAGE: pain as main domain and no self-care difficulty	1
Minimal difficulty on one and none on other	4
Completely different main domain	17

**Pain was included in this category only if not mentioned in 'Pain and mobility' category.

6.3.1 'Completely different'

Of the 32 'different' profiles, 17 were highly problematic, as there was little or no overlap between the two sets of questions. This is just under one quarter of the respondents. Some good examples are the following, where the main domain is given first:

Respondent 4:

WG Short Set: Seeing with lesser difficulty on hearing and cognition

SAGE: Sleep with lesser difficulty on cognition and pain

Respondent 27:

WG Short Set: Concentration with lesser difficulty on mobility

SAGE: Pain and affect

Respondent 65:

WG Short Set: Cognition and self-care, with lesser difficulty on hearing and mobility

SAGE: Sleep and pain and affect, with lesser difficulty on mobility, cognition and self-care.

Of the 17 completely different profiles, five had one or two of the lesser difficulty domains that did overlap, especially if there were a number of domains reported with difficulty. While the *main* domains may differ in the 'different' category, there remains overlap on the domains reported with less difficulty across the two profiles for each respondent – 52 out of the 69 respondents had overlap, albeit of different amounts, of domains reported as being difficult.

6.3.2 Additional domains of SAGE and WG Short Set

The SAGE additional domains were affect, pain and sleep, and the WG Short Set additional domains were hearing and communication. Three respondents reported difficulty on hearing which was not included in the SAGE questions.

If all the reported difficulties of any one respondent is considered, there were 45 instances of reported difficulty on the SAGE additional domainsfor respondents with the 'same' profiles, and 42 for those with 'different' profiles. One respondent may have more than one of these instances, giving a total of more than 69. Some examples of such respondents are as follows:

a) '***Same' profiles*:**

Respondent 21:

WG Short Set: Cognition with lesser difficulty on mobility

SAGE: Cognition with lesser difficulty on pain, sleep, sensory and mobility.

Respondent 45:

WG Short Set: Mobility with lesser difficulty on self-care and seeing

SAGE: Sleep with lesser difficulty on mobility, cognition, pain and sensory

b) *'Different' profiles*:

Respondent 17:

WG Short Set: None

SAGE: Sleep

Respondent 48:

WG Short Set: Seeing and Mobility

SAGE: Sleep and Affect with lesser difficulty on pain, mobility and cognition.

There is a high reporting of difficulties on the additional SAGE domains, and these are often reported as the main domain of difficulty on the SAGE profiles. The WG Short Set main domains are reported with lower levels of severity on the SAGE profile, than they are on the WG Short Set profiles. In other words, the additional domains of SAGE tend to overwhelm and cover the main domains on the WG Short Set.

6.3.3 Mobility and Pain

The analysis presented in Table 8underscores the close relationship between mobility and pain (and self-care and pain in one instance). In total, 31 respondents reported mobility difficulty on the WG Short Set and pain on the SAGE. Pain tended to take precedence in the SAGE profile, as it was reported as more problematic (greater difficulty) than mobility by many respondents. The question arises as to which is primary in occurrence – the pain or the mobility difficulty. Given that pain is a body function or symptom and not an activity in itself, one can postulate that the pain is the dominant feature for the person, and its impact on functioning, typically in mobility and self-care activities, is secondary. When given the option of reporting difficulty on both pain and mobility or self-care, reporting of pain dominates in severity over mobility. If there is no option of reporting on pain, the reporting of mobility and self-caredifficulties becomes the dominant reported difficulty.

Pain is difficult to measure using a single question and hence is not included in the WG Short Set. The WG Extended Set uses more than one question as described in Chapter 5. However, the above results suggest that mobility difficulties could be seen as a proxy of sorts for pain, as only nine instances of reporting pain without also reporting mobility difficulties were observed in the 69 functioning profiles, compared to 31 respondents reporting mobility difficulty on the WG Short Set and pain difficulty on the SAGE.

6.3.4 Remembering and Affect

In Chapter 5, I discussed the interpretation of 'difficulty remembering' as being 'emotional remembering' or being difficulties with memories rather than difficulty with the function of memory. This finding provides a possible explanation for the eight instances of remembering difficulty being reported in the WG Short Set coupled with affect difficulty in the SAGE. This is merely a hypothesis, substantiated by some evidence of similar misinterpretations by the 69 respondents[47] (in addition to the 10 respondents' interpretations reported on in Chapter 5). This hypothesis warrants further investigation in a separate study.

6.3.5 Conclusion on comparison between WG SS and SAGE questions

The analysis I provide in this section highlights a number of issues. Firstly, more respondents have the same or similar functioning profiles for the WG Short Set and SAGE questions, than those who have completely different profiles. This is a positive feature and confirms that the two sets are measuring similar things. Secondly, the additional domains of affect, pain and sleep elicit more responses of difficulty than the WG Short Set, which is limited to only six domains. These additional domains are often reported as the main domains of difficulty, with the main domains of the WG

[47] The data for this are not presented as the numbers are small as not all 69 respondents described the reasons for their responses. It just happened that a few respondents were quite chatty, when answering the standard set of questions on the semi-structured interview, giving a few examples of narratives on their interpretations.

Short Setbeing reported with lesser difficulty (on the SAGE profiles) compared to how they are reported on in the WG Short Set profiles.

There are a number of other possible reasons for a lack of a full match between the WG Short Set and SAGE profiles, which warrant investigation beyond this thesis. These include: a) the placement of the questions relative to each other, as placement does affect responses provided (Meltzer, 2003; Willis 2005). In the questionnaire the WG Short Set questions preceded the SAGE questions and may have built up a sensitization to the topic of the questions; b) the number of questions included in each domain (Meltzer, 2003). The SAGE profiles have more questions per domain than the single question of the WG Short Set domains; c) other unknown factors related to the interpretation of the SAGE questions that have not been investigated as far as can be established, and where no evidence was found in the 69 interviews.

These findings support the decision to limit the analysis to the SAGE profiles, which provide similar but more expanded profiles than the WG Short Set. Given the historical timing of the data collection,[48] it was not possible to use the WG Extended set questions in the semi-structured interviews. The WG Extended Set questions include the domains of affect (anxiety and depression asked separately), pain and fatigue. I have made an assumption that the sleep domain of the SAGE is measuring a similar aspect of functioning as fatigue in the WG Extended Set. My assumption is based on the notion of fatigue as a lack of energy and problems with sleep generating fatigue. The SAGE question asks: 'In the last 30 days, how much of a problem did you have with sleeping, such as falling asleep, waking up frequently during the night or waking up too early in the morning?' The WG Extended Set asks: 'Do you have frequent feelings of being tired?'

[48] The 69 interviews were completed 10 months prior to the cognitive testing of the WG Extended Set through the 10 in-depth interviews described in Chapter 5.

Given the presence of these additional domains in the WG Extended Set, it is hypothesised that similar findings would be obtained on the WG Extended Set as is described here for the SAGE. Notably, it would interesting to see if the WG Extended Set profiles foreground the difficulties with affect, pain and fatigue and 'background' the more traditional categories of the WG Short Set as is noted in the SAGE/WG Short Set relationship.

A point to note is that the WG SS and SAGE were developed for slightly different purposes. The WG SS aimed to develop internationally comparable measures of disability (Washington Group 2008), while the SAGE and its predecessor, the WHS, aimed to measure population health, including functional status, or health states (Task Force on Health Status 2005; Sankoh 2010). Nevertheless, both are measuring the same underlying construct of human functioning, and, furthermore, the WG Extended Set includes the same additional domains as the SAGE.

6.4 Life context factors

The semi-structured interviews asked questions on a range of life context factors described in detail in the analysis section in Chapter 3. The details of how these responses coded are presented in section 3.8.2 b) in Chapter 3. Two composite factors were created from the coding set out in Chapter 3. The two new composite factors were: a) income and assets, and b) social support. The combination of life factors for these are described in Table9.

The context of Agincourt is one where there is a high dependency on social grants, such as old age pensions, child support grants and disability grants. These are non-contributory social cash transfers to people who are poor with the additional criteria of elderly, a caregiver of a child or disabled, respectively (De Koker, De Waal & Vorster 2006).

Table 9: Two composite life factors

Life areas	Subareas included	Rating
1. Income and assets	• Any social grants • Any income other than social grants • Assets • Ability to save	1 = Income group 1 (no social grants or regular income; chickens only or nothing; no saving) 2 = Income group 2 (1 or two social grants or some relatively regular income; vegetables or chickens; occasional saving) 3 = Income group 3 (more than 2 social grants and/or some regular income; chickens and goats; saving quite regularly) 4 = income group 4 (Social grants and/or other regular income; chicken, goats and cows; regular savings)
2. Social support	• Household structure • Social networks • Membership of organisations	1 = limited support (living alone; no contacts beyond immediate neighbours or family; not a member of any organisations) 2 = moderate support (living with 2 or 3 household members; limited contact beyond the village; membership of at least the burial society) 3 = good support (living with a range of household members; visit friends and family beyond the village; membership of two or more organisations)

6.4.1 Type of difficulty in relation to life context factors

Table 11[49] summarises the main features of respondents' life context, functioning type and severity by domain of difficulty. The table only includes those respondents with at least mild ratings on their TFS, and excludes all respondents who have no difficulty. The single most notable association is between reporting a health condition and reporting some functioning difficulties. All respondents in these profiles (except for one who did not give any information) reported a health condition. A full description for each respondent is presented in Appendix 7. A further analysis of the association between reported health condition and reported difficulties is presented later in this chapter.

Most respondents reported being satisfied with their life (21 out of 35), while four respondents felt unsatisfied and 11 were non-committal in their statements when asked if they were satisfied. The respondents who were 'not satisfied' had difficulties predominantly with sleep or pain.

[49] Because of the size of Table 11 it appears in the text after Table 10 resulting in the automatic number formatting of tables allocating it the number 11 and not 10.

There are no other obvious associations from Table 11, such as between the type and severity of profiles and factors such as income group, social support and religious beliefs. While one should avoid generalising from the small sample, this finding does suggest that the measures of disability reflect predominantly health and health related aspects of people's lives and their wellbeing. Furthermore, the limited range of socio-economic status in Agincourt, as I describe in Chapter 3, may have resulted in few differences.

This conclusion may seem contradictory to the high reported levels of anxiety, depression, sleep difficulties and pain, discussed earlier in this chapter, and, specifically, with the notion that these difficulties are a reflection of adverse condition that people live in, rather than more medical causes, as discussed in Chapter 5. The reasons for this could stem from the way questions on life factors were asked. A more detailed probing into the different factors may allow one to see more patterns of association. Nevertheless, the analysis presented here provides a useful starting to point to undertake such explorations.

More women reported difficulties than men. Out of the total of 44 women interviewed, 26 (59%) reported difficulties, compared to only nine of 26 men (34%). Proportionately more women than men reported difficulty with affect, while men were more likely (proportionately) to report difficulty with sleep. Two out of nine men reported sensory difficulty (difficulties in seeing for SAGE) compared to only one woman out of 26 women with such difficulties. Only women reported difficulty in cognition, focusing on remembering, and mobility. Pain was reported by similar proportions of men and women.

In terms of age, the pattern is as expected, with increasing number of respondents reporting difficulties with increasing age:

a) 1 out of 8 respondents 18 – 39 years of age had difficulties (20% within age group)
b) 10 out of 20 respondents 40 – 69 year of age had difficulties (50% within age group)

c) 26 out of 33 respondents 60 – 79 years old had difficulties (79% within age group)

d) 6 out of 7 respondents 80 years or older had difficulties (86% within age group).

Older respondents were more likely to report difficulty with sleep and pain.

As the association between reported health conditions and functional status was the most clear (shown in shaded columns in Table 11), I analysed these data further. In Table 10, I present a summary of the match between the type of health conditions reported for each type of difficulty according to the main domains reported. The data presented in Table 10 include information from all respondents with difficulties, and exclude those with no difficulty, even if they reported a health condition, or those with unclear responses on the nature of their health condition. A respondent was coded as 'matched' if the description provided on their health condition showed a direct link to their functional limitations. Those respondents coded as 'unmatched' showed no link between their reported health condition and their functional difficulties. Those coded as 'partial match' showed some links between their reported health condition and functional limitations. Examples of each code are provided below.

i. <u>Matched</u>

These respondents all described health conditions that can explain the difficulties they reported.

Respondent 1 reported trauma from a gun accident which 'crippled' her arm. This is consistent with a report of pain.

Respondent 14 reported foot and knee pain and being very tired; she described what she thought was anaemia and also reported pain. Her main domain of difficulty was sleep. Problems with sleep are consistent with feeling tired all the time, as I explained earlier in relation to the wording of the SAGE question on sleep.

Table 10: Match between the self-reported health condition and main domain of difficulty

Matched (14)	Cognition/pain = 1 Pain/sleep = 1 Sleep = 1 Pain = 3 Mobility/cognition = 1 Pain/sensory = 1 Pain/mobility = 2 Sensory = 3 Pain/affect = 1
Unmatched (17)	Affect = 4 Sleep = 9 Sleep/affect = 2 Pain/sleep = 2
Partial match (15)	Pain/sleep = 2 Pain/affect = 1 Sensory/affect = 1 Cognition = 2 Sleep = 5 Mobility/sleep = 1 Pain/sensory = 1 Sleep/affect/pain = 1 Sleep/affect = 1

Respondent 20 reported that her muscles stopped functioning and her legs started to have sores and pain; she felt pain in her whole body. Her main difficulty was with pain.

Respondent 22 was confined to bed and unable to walk; he suffered a stroke and was unable to do anything for himself. His main domains of difficulty were pain and affect.

ii. Unmatched

These respondents described health conditions that were not clearly linked to the difficulties they reported. All reported difficulties in sleep or affect, suggesting that their difficulties were less related to their health condition than more general reactions to hardship and adversity.

Respondent 4 reported a knee injury but sleep was his main domain of difficulty.

Respondent 15 reported pain in her legs, problems with her eyes and high blood pressure. Her main domain of difficulty was sleep.

Respondent 23 reported having back pain and problems seeing. Her main domain of difficulty was affect.

Respondent 32 reported vision problems. He complained that he had failed his eye test for his driver's licence renewal because of these problems. He has high blood pressure and takes medication. His main domains of difficulty were pain and sleep. His vision problem could be a consequence of high blood pressure.

iii. Partial match

These respondents showed some correspondence between the health condition and the difficulties they reported. However, this match was not as concordant as that of the matched examples provided above.

Respondent 35 reported high blood pressure, eye problems and some dizziness at times. She took medication for her blood pressure and reported pain all over her body. Her main domains of difficulty were mobility and sleep.

Respondent 36 reported heart attack problems since giving birth. She had diabetes and used insulin injections, got tired easily and had some unspecified spinal cord problems which gave her intermittent pain. She said she had no health condition, but was coded as having one given the extent of her descriptions. Her main difficulties were pain and sensory. The sensory difficulties could be a consequence of poorly managed diabetes.

Respondent 50 reported having aching bones and body. His main domain of difficulty was sleep, although pain was also reported as being an area of difficulty, but to a lesser degree.

Respondent 65 reported problems with a sore hand and muscle weakness. She could not use her affected hand but said it is not a very severe difficulty. Her main domains of difficulty were sleep and pain.

The data presented in Table 10 show that 'unmatched' instances were the most prevalent, followed by 'partially matched' ones. The 'unmatched' domains were, predominantly, affect and sleep and combinations of these two domains. The 'matched' instances were concentrated around the domains of pain, cognition, mobility and sensory difficulties. The 'partially matched' instances included a mix of domains seen in both matched and unmatched instances.

The 'matched' and 'partially matched' instances reflect clear instances of disability as a consequence of a health condition. It is not clear what the 'unmatched' instances reflect, but one explanation could be that the health condition and reported functional difficulties are parallel characteristics of the individual, and not in a causal relationship, as noted for the 'matched' and 'partially matched' instances. The respondent may have a health condition, such as high blood pressure, and parallel to this may experience feelings of anxiety, depression, or sleep problems for a different reason, such as not being able to meet his or her family's needs. This is consistent with the analysis I present in Chapter 5 in relation to the narratives for the domains of anxiety, depression, cognition (albeit as misinterpretations) and fatigue, particularly, and pain to some extent.

6.4.2 Severity of difficulty in relation to life context factors

The results presented in Table 12 are for all 69 respondents, including those with 'no difficulty'. The results in Table 12 are similar to those presented in Table 11, but categorized according to severity of difficulty and not type of difficulty, based on the total functioning score for each respondent. Since the analysis for Table 12 looks at the association (non-statistical) between the severity of the difficulty (based on the TFS) and life context factors, the 'no difficulty' profiles must be included to look at the association of no reported difficulty with the life factors.

a) No difficulty (N=21)

Of the 21 respondents with no difficulty, the majority were satisfied with their lives, three were dissatisfied and one did not state their level of satisfaction. None of these respondents reported being disabled, and eight out of 21 reported no health conditions. The majority were in the two higher income groups (12 respondents), and four had a high level of social support. None of the 21 mentioned anything about religious beliefs.

b) Mild difficulty (N=17)

For the 17 respondents with mild difficulties, the majority were satisfied with their lives, and two identified as 'disabled'. A much higher proportion reported a health condition compared to the respondents with 'no difficulty'. The respondents were spread evenly across the income groups, and the majority described 'some' social support (14 respondents), three 'no' social support, and no respondents 'much' social support. There was an even spread between respondents who made some religious statement, although there were slightly more who did not mention any.

c) Moderate difficulty (N=17)

For respondents with moderate difficulty, nine reported being satisfied with life, compared to three not satisfied and five being non-committal. Four respondents said they were disabled and all reported having a health condition. Similar numbers of respondents were in the lowest two and highest two income groups. Three respondents had limited or no social support, and one had the highest level of support. Eight respondents mentioned religious beliefs. The most frequently mentioned domains of difficulty were affect (5), sleep (5) and pain (4). The domains of cognition, sensory and mobility were reported each by two respondents.

d) Severe difficulty (N=9)

Of the nine respondents with severe difficulty, four reported being satisfied with their lives, two were not satisfied and three were non-committal. Five out of the nine identified as being disabled

Table 11: Summary of main difficulty profiles based on highest scoring domain in TFS (Respondents with difficulties and sufficient information on life context factors)

Type of difficulty profile	Age 1=18–39 yrs 2=40–59 yrs 3=60–79 yrs 4=80+yrs	Sex	Severity	Life satisfaction (DK includes non-committal)	Self-reportedDisability status	Self-reported Health condition	Income group	Social support	Religious statement
Sleep (N=12)	1 = 0 2 = 2 3 = 10 4 = 0	F= 8 M = 4	Mild = 6 Moderate = 4 Severe = 2 Extreme = 0	Yes = 9 No = 2 DK = 1	yes = 3 No = 9	Yes = 12 no = 0	1 = 3 2 = 4 3 = 3 4 = 2	None = 4 Some = 7 Much = 1	Yes = 4 No = 8
Affect (N=6)	1 = 0 2 = 2 3 = 3 4 = 1	F = 5 M = 1	Mild = 2 Moderate = 4 Severe = 0 Extreme = 0	Yes = 4 No = 0 DK = 2	yes = 3 No = 3	Yes = 5 no = 0 DK = 1	1 = 2 2 = 2 3 = 2 4 = 0	None = 1 Some = 5 Much = 0	Yes = 3 No = 3
Pain (N=9)	1 = 0 2 = 2 3 = 5 4 = 2	F = 7 M = 2	Mild = 2 Moderate = 4 Severe = 2 Extreme = 0	Yes = 5 No = 2 DK = 1	yes = 2 No = 6	Yes = 8 no = 0	1 = 0 2 = 4 3 = 2 4 = 1	None = 0 Some = 7 Much = 0	Yes = 4 No = 4
Sensory (N=3)	1 = 0 2 = 1 3 = 0 4 = 2	F = 1 M = 2	Mild = 1 Moderate = 1 Severe = 1 Extreme = 0	Yes = 1 No = 0 DK = 3	yes = 2 No = 1	Yes = 3 no = 0	1 = 1 2 = 0 3 = 2 4 = 0	None = 0 Some = 3 Much = 0	Yes = 0 No = 3
Cognition (N=3)	1 = 1 2 = 2 3 = 0 4 = 0	F = 3 M = 0	Mild = 1 Moderate = 1 Severe = 0 Extreme = 1	Yes = 1 No = 0 DK = 3	yes = 1 No = 2	Yes = 3 no = 0	1 = 0 2 = 3 3 = 0 4 = 0	None = 1 Some = 2 Much = 0	Yes = 0 No = 3
Mobility (N=2)	1 = 0 2 = 1 3 = 1 4 = 0	F = 2 M = 0	Mild = 0 Moderate = 1 Severe = 0 Extreme = 1	Yes = 1 No = 0 DK = 1	yes = 0 No = 2	Yes = 2 no = 0	1 = 0 2 = 0 3 = 1 4 = 0	None = 0 Some = 1 Much = 0	Yes = 2 No = 0

Table 12: Summary of main difficulty profiles based on highest scoring domain in TFS (All respondents with sufficient information on life context factors)

Severity of functioning profile	Age 1=18–39yrs 2=40–59 yrs 3=60–79 yrs 4=80+yrs	Sex	Type of functioning profile	Life satisfaction (DK includes non-committal responses)	Self-reportedDisability status	Self-reportedHealth condition	Income group	Social support	Religious statement
None (21)	1 = 5 2 = 7 3 = 8 4 = 1	F= 13 M = 8	N/A	Yes = 17 No = 3 DK = 1	Yes = 0 No = 20	Yes = 8 no = 13	1 = 0 2 = 9 3 = 8 4 = 4	None = 0 Some = 17 Much = 4	Yes = 6 No = 15
Mild (17)	1 = 2 2 = 5 3 = 10 4 = 0	F = 11 M = 6	Affect = 2 Sleep = 6 Sleep/affect = 1 Pain/sleep = 2 Pain/affect = 2 Pain = 2 Cognition = 1 Sensory = 1	Yes = 14 No = 0 DK = 3	Yes = 2 No = 15	Yes = 15 No = 1 DK = 1	1 = 4 2 = 6 3 = 5 4 = 2	None = 3 Some = 14 Much = 0	Yes = 7 No = 10
Moderate (17)	1 = 0 2 = 5 3 = 9 4 = 3	F = 12 M = 5	Cognition = 1 Pain = 2 Affect = 4 Sleep = 4 Sensory = 1 Mobility = 1 Pain/sensory = 1 Sleep/affect = 1 Pain/mobility/cognition=1	Yes = 9 No = 3 DK = 5	yes = 4 No = 13	Yes = 17 no = 0 DK = 0	1 = 2 2 = 6 3 = 7 4 = 1	None = 3 Some = 12 Much = 1	Yes = 8 No = 9
Severe (9)	1 = 0 2 = 2 3 = 5 4 = 2	F = 5 M = 4	Pain = 2 Affect/pain = 1 Pain/sleep/affect=2 Sleep = 2 Sensory = 1 Pain/sleep = 1	Yes = 4 No = 2 DK = 3	yes = 5 No = 4	Yes = 9 no = 0	1 = 4 2 = 2 3 = 2 4 = 1	None = 2 Some = 7 Much = 0	Yes = 0 No = 9
Extreme (3)	1 = 1 2 = 1 3 = 1 4 = 0	F = 2 M = 1	Cognition = 1 Mobility = 1 Pain/sensory/mobility=1	Yes = 0 No = 0 DK = 3	yes = 1 No = 2	Yes = 3 no = 0	1 = 1 2 = 1 3 = 1 4 = 0	None = 0 Some = 3 Much = 0	Yes = 1 No = 2

and all had health conditions. Four were in the lowest income group and five in the remaining three income groups. Two had the lowest level of social support and none had the highest level. None mentioned any religious beliefs.

Pain was reported by six respondents as being a problem, sleep by five respondents, and affect by three respondents. Sensory was the only other domain reported as being difficult for the respondents with severe difficulty.

e) Extreme difficulty (N=3)

None of the three respondents in this category were satisfied with their lives and all gave non-committal responses. Only one identified as being disabled and all three reported health conditions. The three respondents were spread across the lower three income groups and all had the mid level of social support. One of the three mentioned religious beliefs.

Only four domains were reported as being the main area of difficulty; viz. mobility (2), pain (1), sensory (1) and cognition (1). Only one of the three respondents had more than one 'main' domain. However, given the extreme rating of the TFS of these three respondents, the other domains were also reported with more than mild difficulty.

f) Effect of sex and age on severity

The proportions of men and women represented in the severity categories were similar in all five categoriesof severity as this was stipulated as a selection criterion. The age pattern across the five categories varied, with the highest proportion of the youngest age group being in the 'no difficulty' category, and the highest proportion of the oldest group being in the moderate and severe categories. The two middle age groups showed a spread across the 'no', 'mild'and'moderate' difficulty categories. The extreme category had one each of the three youngest age groups and none of the oldest group

respondents. The sample size is too small and purposive in nature to draw any conclusions from this. However, the possible trend of younger people being more likely to report extreme difficulty, may be related to older people seeing these difficulties as part of normal life and being more accepting of these. This was reflected in the comments on this theme presented in Chapter 5.

6.4.3 Conclusion on the effect of life factors on responses

The analyses provided in Tables 11 and 12show some interesting, but not unexpected trends. Overall, the domains of pain, affect and sleep are the most likely to be reported as severe difficulty, while the more traditional domains of disability (cognition, mobility and sensory difficulty) are reported as having extreme difficulty. However, the small numbers make it impossible to determine whether these are real trends or merely artefacts of the sample size.

a) Life satisfaction

The majority of the respondents reported being satisfied with their lives[50], but the majority of the remaining respondents were non-committal, suggesting that they were not sure what they were feeling. The more severe the TFS, the more likely the respondents were to give a non-committal response. This pattern suggests that having difficulties makes one unsure about one's level of satisfaction or that being dissatisfied leads one to reporting difficulties. There was no clear pattern of specific domains being more associated with dissatisfied or non-committal responses on life satisfaction. While I did not use an external assessment (for example by a rehabilitation therapist) of the respondents' functional status, I did observe the majority of the interviews and was able to note when there were serious functional problems or not. My observations were that the severity of reported difficulties were generally reasonably congruent with the response provided by the respondents. Some were more obvious than

[50] The rating of life satisfaction was done based on an open ended question and not a formal assessment, such as the application of a quality of life scale.

others, such as a wheelchair user, a blind man, and a man paralysed by a stroke. These observations serve as additional evidence of the close relationship between reported and observed difficulties.

b) Income group, social support and religious beliefs

While these three life context factors show some weak associations with the type and severity of the functioning profiles, these are limited and inconclusive. The reasons for this lie in the limited information obtained through the use of semi-structured interviews. I discuss this further under limitations of my study in Chapter 8.

c) Sex and age

Proportionately, women are more likely to report difficulties with affect than men, and men more likely to report difficulty with sleep. Older respondents seem to experience more problems with sleep and pain. If reported anxiety and sleep difficulties are proxies for other problems related to hardship and adversity, as I have argued in Chapter 5 and earlier in this chapter, the trend suggests that women report these as anxiety and men as sleep problems. The age effect of increased problems with sleep and pain are consistent with problems of ageing, such as age related aches and pains.

d) Disability status

Proportionately, fewer respondents with pain and sleep difficulties identified as being disabled than those with affect and sensory difficulties. Neither of the two respondents with mobility difficulty identified as being disabled. Sensory difficulties are generally understood as being a traditional disability category, as in blindness or low vision, while affect, especially as a common mental health disorder, is not. This possible trend needs further investigation. In terms of severity, increasing proportions of respondents identified as being disabled with increasing severity. None of the respondents with 'no difficulty' reported being disabled, but over half of those with severe difficulty did report being disabled.

e) Health condition

Only one respondent with difficulties reported no health condition, while eight of the 21 respondents with no difficulty reported a health condition. This is one of the strongest associations noted in Tables 11 and 12. The reported health condition is not necessarily related to the type of domain difficulty. For example, a person with sleep difficulty may report having high blood pressure or diabetes, and his or her difficulty may not be related to those health conditions. However, these measures of disability are clearly picking up something about people's health and health related wellbeing.

6.5 Chapter conclusion

The questions asked at the start of this chapter can now be answered. Firstly, the severity and type of difficulty profiles show the dominance of difficulties with affect, sleep and pain or combinations of these. Few profiles with the traditional disability domains were noted. Secondly, there are few notable associations between these severity and type of difficulty profiles and life context, except with the presence of a reported health condition. Thirdly, the response profiles of severity reflect results found in other studies, where most people have mild difficulties and less people have severe difficulties (StatsSA 2006; WG/UNESCAP 2010).

The comparison between the WG SS and SAGE identified from differences in the type of profiles obtained when additional domains are included. Thisconfirms the distinction I made in Chapter 5 between basic activity and feeling domains. They seem to be tapping into different constructs within disability and this needs further investigation. I take up this point in the integrated discussion in Chapter 7.

Chapter 7

Discussion

The aim of my thesis was to evaluate existing measures of disability, with specific reference to the role of wording, question understanding and interpretation, and people's life context in determining their responses to questions on functioning. As I indicate in the first chapter, I focus on one location, South Africa, as a case study, but with the purpose of contributing to the international work in the field of survey methodology in the field of disability. I evaluated existing sets of questions that measure basic activities and feeling domains as relevant components of disability. In chapters 4, 5 and 6, I present the analysis and results of my study and discuss these in some depth. In this chapter, I integrate the findings into a discussion addressing the major themes raised in the literature review and in the discussion from chapter 4, 5 and 6. The themes I address are:

- the validity of the disability measures (Section 7.1)
- the implications of using inclusive and transparent measures for disability statistics (Section 7.2)
- the difference between the basic activity and feeling domain questions (Section 7.3)
- the implications of my findings for how we understand disability (Section 7.4)
- and the difference between measuring functional status and disability identity (Section 7.5).

7.1 The goodness of performance of the basic activity and feeling domain questions

In the introduction, I discuss different elements of validity testing and contextualise the contribution of my thesis as focused on three non-statistical aspects of validity; namely, content, response process and face validity. My exploration of the effect of wording, question interpretation and associations with life factors is the source of the evidence to support the determination of validity, or the extent to which a test or series of questions measure what they are supposed to measure (Parry &Crossley 1950). In

addition to validity, I discussed the importance of transparency in measures to ensure accurate understanding and interpretation of the statistics.

7.1.1 Validity of the measures

In Chapter 2, I set out the different components that should be considered in assessing validity of survey instruments. I raised the concern noted in the literature on the need to go beyond face validity (Messick 1995; Cook & Beckman 2006), and to include a more detailed analysis of validity using rigorous methodologies. The elements to assess to determine validity noted in Chapter 2, include content evidence which focuses on the construct being measured, the response process which is self-evident, and face validity.

The construct underlying the questions I evaluated is disability. As described in Chapter 2, disability is a complex and multidimensional construct comprising a number of different components. For full measurement of disability, all these different components must be included in some way or another. I have evaluated only part of the construct of disability by focusing on basic activity and feeling domains. The first reason I gave for this was that these components are basic to all human functioning and are least likely to be significantly influenced by cultural and other context factors. Walking, seeing, hearing, remembering, self care, communication and the feeling domains are basic functions for any person. How difficulties in each are expressed, may, nevertheless, be culturally and contextually influenced, which was part of what I investigated. The second reason, linked to the first reason, is that these components have been given the most attention in developing measures. The existing measures I used are, thus, focused on basic activity and feeling domains. The SAGE does include measures for more complex activity domains, but I did not select those questions for my evaluation.

The conclusion from my results is that the basic activity domain questions perform well and show good content evidence as reflected in the effective response process. The exception is the domain of cognition, as I have discussed extensively in Chapter 5, which performs more as a feeling domain. For the feeling domains, the constructs of anxiety, depression, fatigue and pain seem to be well reflected in the narratives of respondents, as they described these feelings accurately. However, the scope of what degree of difficulty is considered a problem or not (i.e. 'disabled') was not clear. The high endorsement of difficulties in these feeling domains suggests the need to investigate this further. The concordance between the interpretations by the Shangaan respondents and the intent of the functioning questions for all except one domain – cognition – suggests that the questions are measuring what is intended; in other words, they are performing well and generate accurate statistics. The next question is how to interpret these statistics, specifically for the feeling domains. But that is a question that goes beyond the scope of my thesis.

Furthermore, I consider face validity in my thesis, but not in as a single or simplistic measures, as described by Cook and Beckman (2006) and Sartori and Pasini (2007). The concordant interpretations coupled with comments by respondents of the relevance of these questions in their lives, suggests that the measures do have face validity. Face validity is noted as an important criterion in selecting domains for measuring health status and functioning, by the Task Force on Health Status (2005b). The CASM approach to question evaluation, coupled with complementary approaches of assessing the effect of wording and life context factors, avoids a simplistic approach to non-statistical validation. Content evidence and response process information are added to face validity information.

The validity of the measures are limited to the questions that I evaluated – the WG Short and Extended Sets, and the selection of SAGE questions, all of which cover the realm of basic activities (seeing, hearing, walking/climbing, cognition, self care, communication) and body function (anxiety and

depression, pain, fatigue/sleep) (WHO 2001) in the ICF. [51] If we can demonstrate that measurement of basic activities generates valid and transparent statistics, we can encourage a developing praxis of using these measures on a routine basis and in an integrated manner. Furthermore, once we have established good measures of basic activities, it facilitates the process of developing measures for the other elements, including complex activity domains, the impact of environmental factors on basic and complex activities, and environmental factors themselves.

7.1.2 Transparency of the measures

The results I presented in Chapter 4, allow me to conclude, and I use the term with care as I understand my findings on the word level to be conclusive, that the use of 'difficulty' results in a measure that is more transparent and inclusive than questions asking about 'disability' as pertains to English and the nine other South African languages I included in my study. The categorical measures, embodied in questions such as 'Are you disabled?', the South African Census 2001 questions, or the questions asking about being 'blind, deaf, crippled, or mentally retarded' (UNSD n.d), reinforced the individual or medical perspectives of disability (Humphries & Gordon 1992; Barnes, Mercer & Shakespeare 1999). The continued use of these categories of impairments in many censuses (UNSD n.d.), across many, largely developing countries, is, therefore, of concern. In addition, these categorical questions (except maybe for 'Are you disabled?') yield more confusion than clarity on what is being measured. These are not useful questions for measuring severity, multi-domain functional level or identity. They do not have construct validity, as it is not clear what construct is being measured. 'Difficulty' measures functional

[51] As explained in earlier chapters, the domain of fatigue was included in the WG Extended Set and the sleep in the SAGE. But both measures intended to measure problems with level of energy and, hence, have been analysed as the same or similar domains.

status, and 'disability', at best, measures a notion of identity, and at worst, a confused construct related to disability.

The WG Short and Extended Set, SAGE questions and 'Are you disabled?' are better measures of disability. They are transparent in what they are measuring, and draw our attention to the different aspects of disability – difficulties in doing various activities for the first three sets (WG Short and Extended Sets and SAGE) andthe identity as 'disabled' for the last question.

7.1.3 Reference group effect

The notion of a reference group was discussed in Chapter 2, and is important to consider when developing internationally comparable measures (Heine et al. 2002; Albaum 1997). This notion has largely been documented for responses to Likert Scale items, which require a response of agreement or disagreement with given statements, usually about attitudes. I found no evidence of reference group effect related to cultural norms and practices (Heine et al. 2002; Albaum 1997). This reinforces that basic activity and feeling domains are basic to human functioning. This is further reinforced by the similarity in findings on the question performance, of my results and those of the WG/UNESCAP study (UNESCAP 2010). The 150 cognitive testing interviews undertaken as part of the WG/UNESCAP study showed little variation in the range of interpretations for the WG Extended Set, and the literature shows *etic* similarities in the presence of common mental health disorders even if these are expressed differently or *emically*across cultures. In other words, there are generic understandings of the notions intended in the measures for the feeling domain, but there are culture specific ways of expressing these. A good example of this is the 'idiom of distress' and its relationship with common mental health disorders, as discussed in more detail below.

However, I did find evidence of a reference group effect related to physical and geographical context. This was particularly noted for the domains of mobility (walking and climbing stairs) and lifting a 2 litre jug of water (upper body function as part of the self care questions). The context of Agincourt, as described in Chapter 3, requires large distances to be covered between villages and to access health care services. Transport is expensive and limited. As I show in Chapter 4, a number of respondents reported difficulty on the WG Short Set question on 'walking and climbing stairs' but no difficulty on walking distances of 500 metres or climbing a flight of stairs. The respondents' reference group is that of walking long distances on a regular basis. Their responses to the WG Short Set question on 'walking and climbing stairs' is relative to this reference. They reported difficulty walking, but when asked to explain their responses, gave example of walking distances of five to twenty kilometres. Because the question on 'walking and climbing stairs' does not specify a reference, this reference group effect may explain differences between contexts such as AHPU, and ones where there is good transport and little need to walk long distance. This is a limitation of the WG Short Set question that must be borne in mind when comparing statistics from different contexts. This limitation can be effectively managed by the use of an extended set of questions, as is the case for the WG Extended Set. The context of fetching water from a communal tap in large containers similarly creates a reference group effect for the question on lifting a 2 litre jug.

7.1.4 Effectives of subjective measures of level of functioning

In Chapter 2, I differentiate between objective and subjective measures of level of functioning. While I conclude from my results that the WG and SAGEquestions I evaluated, are able to provide a reasonably good measure of functional status or level of functioning, I remain cautious in this conclusion. My observations during the interviewing process does not replace a more objective assessment of functioning that could be correlated with subjective assessment of functional status. I base my

conclusion on the close correlation between responses given and the person's functioning that I observed, while sitting in on interviews or conducting them. My observations were informed by my training as a speech-language therapist and audiologist.

7.1.5 Basic activity versus feeling domain questions

The questions I evaluated seem to fall into two distinct groups, as I indicated in chapters 5 and 6. The first are the traditional domains of disability – seeing, hearing, walking and climbing stairs, self care and communication. These are identified as domains of functioning that disabled people are 'unable to do', as described in Chapter 4. A blind person cannot see, a deaf person cannot hear, a wheelchair user cannot walk or climb stairs, people with severe and often multiple difficulties are unable to wash and dress themselves or communicate. Cognition is another traditional disability domain. People who are intellectually or cognitively impaired cannot remember or concentrate. However, the question on remembering and concentrating was misinterpreted by six of the ten respondents in the cognitive testing interviews. These misinterpretations were similar for the six respondents and were about difficulties with memories, thinking too much and struggling to concentrate on tasks involving money matters, when one does not have any, as described in Chapter 5. Thus, the domain of cognition was problematic and performed more like the second group of domains than the first one.

The second group of domains were what I term the feeling domains. They measured feelings that people have, including anxiety, depression, fatigue (or sleep problems) and pain. These domains are classified under body functions in the ICF (Who 2001) and are about mental health. The exception is pain which is closely related to mobility and self care difficulties.

The results presented in chapters 5 and 6 highlight further differences between these two groups of domains. People who reported difficulties with these feelings were less likely to identify as disabled,

whereas the opposite is true for the basic activity domains. Furthermore, difficulties with basic activities generally matched the reported health condition of the respondent, whereas difficulties in feeling domains were not matched. A respondent would report, for example, high blood pressure or diabetes, but report difficulties with anxiety, depression or fatigue. If disability is understood by the respondents as being 'unable to do anything', it is not surprising that those with basic activity limitations identified as disabled, while those who reported feeling domain problems did not identify as disabled. Being anxious, depressed or tired didrender the person 'unable to do anything'. This distinction is interesting as it corroborates with traditional views on disability, but is contrary to that set out in the ICF. The ICF does not differentiate between physical, sensory, intellectual and mental health difficulties. All are considered as disability. What my findings suggest is that people's understanding and current theorizing on disability are not concordant.

A further difference between the two domain groups was in the responses given. A number of respondents, when asked to indicate the frequency of anxiety or depression, responded by saying that they could not measure these in discrete units – one is either anxious or not. This was not the case for the basic activity domains. Respondents were able to differentiate between degrees of difficulty for the latter.

7.1.6 Using response options

The narratives presented in Chapter 5, showed how some of the respondents struggled to apply the given response options when answering the questions. Respondent 3, for example, showed a good understanding of the question intent for all domains, but failed to respond as required using the response options. This can be explained by a number of factors, including her age (77 years old), lack of formal education, and possibly that she did not feel the questions were addressing her main issues. These are all recognised factors that affect people's ability to respond to survey questions (Miller 2003;

Miller et al. 2006), and show the limitations of surveys, in constraining people's responses. Respondents like Respondent 3 are likely to generate missing response data in surveys, but these do not invalidate the questions.

7.1.7 Conclusion on the question performance

In summary, the question evaluation I undertook shows that the measures of both basic activity and feeling domains are valid, for the parameters of validity that I considered. Further validation of these measures would require more statistical methods of evaluation. The evaluations of the basic activity questions produce clear and uncontentious results, and are not discussed further in any detail. However, the evaluations of the feeling domain questions raise a number of issues and concerns. I discuss these further below.

7.2 Implications of 'inclusive' and 'transparent' measures

Having established that these measures are valid, albeit within the elements of validity that I have considered, the next considerations are the implications of using these inclusive and transparent measures.

7.2.1 The inclusive nature of the measures

The inclusive nature of the measures is shown in the increased number of people counted in as 'disabled' on the WG Short Set compared to the Census 2001 question and 'Are you disabled?'. The transparency of the measures is about understanding how the measures work, in particular, the variability of the interpretations that remain concordant with the question intent or that are 'in scope', and those that are discordant with the intent or 'out of scope'. A furtherconsideration is understanding the differences in the meaning of traditional or basic activity and non-traditional or feeling domains of disability.

The inclusive nature of the measures is determined by three factors. The first is using the term 'difficulty' rather than 'disability'; the second is the use of a scale of response options rather than 'yes/no'; and the third is the addition of the feeling domains or non-traditional disability domains, together with the basic activity or traditional domains of disability. This last factor pertains to the SAGE and WG Extended Set, which include these domains, but not the WG Short Set.

The results I present in Chapter 5 show clearly how people are not willing to identify as disabled, but are willing to report difficulties. This is particularly the case for older people and people with chronic illness. The identity of 'disabled' is associated with stigma and discrimination (Baynton 2001; Barnes et al, 2004; Humphries & Gordon 1992), and being a lesser person (Ikäheimo 2009), or being a misfit (Garland-Thomson 2011). I discuss the issue of identity further below, but return first to the implications of using measures that are more inclusive and transparent. The notions of belonging to a group of 'us normal' versus 'them disabled' is strongly reflected in these fears of identifying as disabled. Linked to the notion of disability as loss of ability, was an additional notion of loss – loss of family and loved ones. A number of respondents from the 69 semi-structured interviews, identified as disabled because of having lost their family.

The inclusive nature of questions about 'difficulty' has thepotential to expand the boundaries of who is included in the mainstream as 'normal' and 'not different'. If larger numbers of people are counted as 'disabled', and this is acknowledged publically in the way information is reported and services are provided, it could shift notions of who is disabled and what disability is. In other words, it could widen the 'us' category, and shift disability from a categorical and marginalized identity, to one which is fluid and dynamic. Changes in this identity can arise from changes in the underlying health condition or from changing environmental factors. The statistics generated by inclusive measures identify a larger proportion of the population, including wheelchair users, as having difficulty with transport, for

example, than only including wheelchair users as experiencing such difficulties. The inclusive nature of the measure may, in time, contribute to reducing the marginalization of disabled people.While it is naïve to think that just by changing the way we measure disability, we can change attitudes towards disabled people, I argue that by mainstreaming disability statistics using valid measures, we can increase visibility and awareness of disability. As Baynton (2001) eloquently states, 'disability is everywhere…once you know how to look for it'. My appropriation of this phrase out of the specific historical analysis context referred to by Baynton, serves to describe the implications of using more inclusive measures. These measures reveal how prevalent difficulties in functioning are in the general population, be they temporary ones resulting from accidents or acute illness, or permanent ones. The mainstreaming of disability statistics is only one, in a range of interventions that can weaken the 'us' and 'them' distinctions, and reduce the stigma associated with disability.

Use of a scale of response options further encourages people to report 'some difficulty' which is sufficient to warrant being reported, but not severe enough to say 'yes' if only given 'yes/no' as response options. 'Some difficulty' shifts the notion of disability away from 'unable to do anything' to one that incorporates a range of levels of difficulty. Respondents are able to acknowledge their difficulties without having to take on a 'disabled' identity.

The reported difficulties for the feeling domains were high relative to those for the basic activity domains, as I show in Chapter 6. The reasons for this are complex. Firstly, the fact that, for the respondents, these feeling domains do not seem to be associated with disability, makes it easier to report such difficulties. Secondly, a strong feature of these reported difficulties, in my data, was their close association with adversity and hardship, as was generally the case for the Agincourt respondents. I discuss this second reason in more detail below.

The inclusive nature of the measures,that generate high prevalence estimates of difficulties compared to the traditional categorical measures, may push governments to address the needs of these people. If, hypothetically, 20% of the population report difficulties of varying degree, in walking and climbing stairs, it becomes economically and politically important to provide accessible transport and buildings. If only wheelchair users are counted as having mobility difficulties, the numbers will be small (probably under 1% of the population), and they can be 'managed' in a different and 'separate' way, reinforcing marginalization.

7.2.2 The transparent nature of the measures

The transparency of the measures is illustrated by the insights we gain from the question evaluation which inform how we can analyze the survey data. The respondents' interpretations of the WG Extended Group questions, as analyzed in Chapter 5, give indications ofthe potential respondent-related errors that could be generated in survey data. A good example is that of the interpretations of the questions on affect and cognition. If a high number of people reported cognition problems in a survey administered in a low resource Shangaan community, the interpretation of this high prevalence would be incorrect without the understanding generated by the question evaluation.

7.3 Understanding the performance of the feeling domains

Given the high endorsement rate for feeling domains reported in chapters 5 and 6, I now review some of the features of this finding and present some tentative explanations that can assist the interpretation of the related statistics. The challenges posed by this high endorsement rate are related to, firstly, how we interpret this high rate of difficulties, and, secondly to the meaning of these difficulties. The latter challenge, in turn, determines the intervention route. Should all people who report feeling difficulties be included in the disability statistics? Are these feelings clinical diagnosable mental health conditions or reactions to hardship and adversity? Can the high rates be used as further evidence of the vicious cycle

of poverty and importance of reducing inequities in development, as defined by Sen (1999a)? The domains of particular importance are anxiety, depression, and fatigue or sleep. The domain of pain, although within this group, was less problematic in its interpretation, as many instances of reported pain were associated with reported mobility or self care difficulties.

7.3.1 The meaning of the feeling domains for respondents

Anxiety, depression and related fatigue and problems with sleep, can be generated for a number of reasons, including inherent characteristics of the individual that trigger anxiety or depression, illness that is associated with fatigue, or external triggers. In addition, anxiety and depression are closely related (Moussavi et al. 2007; Lund et al 2011; Patel et al. 2001; Patel et al 2003), and are often associated with fatigue and generalized pain (Gureje 2007; Scobar et al. 2007).

The respondents in my study consistently described these feeling difficulties as related to living in conditions of hardship and adversity. This is congruent with conditions in Agincourt, with poor access to services, limited and costly transport, poor or no access to water, sanitation or electricity, and high levels of unemployment. The respondents described feeling anxious or depressed because of the loss of loved ones, not having sufficient resources to meet their family and household responsibilities, feeling insecure and unsafe, their children not finding employment, and just 'thinking too much'. They seemed to be voicing their dissatisfaction with this hardship by reporting difficulties on these feeling domains.

Difficulties related to anxiety, depression, fatigue or sleep problems were not limiting the respondents' everyday functioning in the same way that difficulties in basic activities limits a 'disabled' person. In other words, disability was understood by respondents as being about inability, while problems with anxiety, depression and fatigue were understood as feelings that are troublesome, but not necessarily affecting one's functional status. The respondents' explanations suggest that these feelings are, in

themselves, an outcome of a complex interaction between respondents and their adverse living conditions. The interaction of the person with these adverse life conditions may lead to depression, anxiety, and fatigue, maybe as a marker of reduced capabilities (Sen, 1999a) or illbeing (as opposed to wellbeing). The evidence for these responses is primarily from the Agincourt respondents, with some evidence from the focus group participants, many of whom lived in rural areas and with varying levels of poverty.

The answer to the question on whether all people reporting feeling difficulties should be counted as 'disabled', is twofold: firstly, the high number of people reporting such difficulties suggests that we need to pay attention to these problems; and, secondly, these feeling domains underpin many activities, and provide a way to understand how they contribute to difficulties in more complex domains. I discuss both of these in more detail.

Affect, pain and fatigue are all classified in the ICF under body functions and not under the Activity/Participation classification, under which the traditional domains are classified (WHO 2001).[52] Body functions are defined as physiological functions of body systems including psychological functions (WHO 2001). They provide an explanation for functional limitations, such as muscle weakness causing difficulties in walking, or are used as diagnostic markers of underlying illness, such as severe psychiatric illnesses or general ill health. Pain is an underlying cause of difficulties in, for example, walking or climbing stairs, and fatigue is an underlying cause of, for example, limited ability to take care of oneself. Pain, affect, and fatigue are symptoms more than activities. Furthermore, many of the difficulties with these feelings were described as 'part of normal life', as presented in chapters 5 and 6. However, for the

[52] Seeing, hearing and cognition are classified as body functions when they refer to the level of vision, while they are activities when they refer to making meaning from sensory experience for seeing and hearing, or being able to use information in making decisions and learning for remembering and concentration.

purposes of generating statistics that are precise and meaningful, we are interested in problems with affect, pain, and fatigue that go beyond what is considered normal or part of daily life, or, as a few respondents commented, due to the fact of being human or 'thinking too much'. The question we need to ask is whether the level of difficulty reported by the respondents in my study warrant inclusion in disability statistics. On the one hand we want to identify all people who experience any difficulty, but on the other hand we do not want to ignore the differences in the experiences of people with only mild problems compared to those of people with more severe difficulties. If we have a measure that is too inclusive, the experiences of people with severe difficulties may be masked by the larger number of people with milder difficulties.

The problem of who to count in as 'disabled' can be resolved, in part, by using further questions on each of these domains, as is present in the WG Extended Set, but not analyzed in my study. However these were analyzed in the field test data from the WG/UNESCAP project (UNESCAP 2010). The analysis consisted of cross tabulations and bivariate logistic regression models of the frequency of a problem such as anxiety, depression, or fatigue, by the intensity of that problem. In addition, the analysis included the response to the probe questions on the type of anxiety. These probe questions were included in the field testing phase of the study to determine the number of people endorsing the different interpretations provided in the cognitive testing interviews. This was only undertaken for those respondents who reported difficulties on the first question for each specific domain - the same question I focused on in my analysis in Chapter 5. The results showed that thoserespondents with, for example, anxiety related to chest pains, anxiety that interfered with their lives, a clinical diagnosis, or limitations in daily activities (all asked as probe questions), were most likely to report 'a lot of' anxiety on a 'daily' basis. Those with anxiety described as 'normal part of life' (another probe question) were most likely to report 'a little' anxiety or 'somewhere in between a little and a lot' of anxiety, and only 'a few times a

year'. Those respondents with anxiety related to economic difficulties (another probe question), were mixed in their responses, but these were predominantly in the 'in between a little and a lot' level of anxiety and occurring 'daily', 'weekly' or 'monthly'. These results confirm, firstly, that anxiety due to economic difficulties is not unique to the respondents in Agincourt, but at least also to respondents in Asian-Pacific countries; and, secondly, that this type of anxiety, while not in the most severe category ('a lot of difficulty daily'), remains an important problem and worthwhile to measure.

The second answer to the question on whether these non-traditional domains should be measured, is that these difficulties underpin many other activity limitations, and, as such, are useful to measure. Statistics on these difficulties generates opportunities to test hypotheses on the relationship between these body functions, or feeling domains, and the activity limitations with which they maybe associated, for example, inability to sustain employment. This is similar to the analysis described by Cambois and colleagues (2005), who showed that difficulties in more complex domains, in their case self care, was almost always associated with difficulties in more basic domains such as vision and mobility.

7.3.2 The relationship between feeling domains and common mental health disorders

In order to understand the meaning of statistics on feeling domains, we can refer to the literature on common mental health disorders and the notion of idioms of distress. I discuss both of these concepts in Chapter 2 and refer to them in the discussion of Chapter 5.

People report distress and reactions to their illness and/or adverse circumstances by reporting pain, often in association with symptoms of depression and anxiety (Gureje 2007; Gureje, Scobar and Sartorius 2007). Gureje (2007), through his work in West Africa, states that the causal pathways of this association between depression and anxiety, on the one hand, and pain on the other are not clear, but that there seems to be evidence for anxiety and depression symptoms preceding or being the

consequence of pain, as well as these being concomitant. He concludes his review of psychiatric aspects of pain by suggesting that chronic, undifferentiated pain which is not linked to any specific physical cause, is associated with common mental health disorders. In my findings, the expression of generalized pain was less evident than the expression of anxiety, depression and fatigue. Pain was more commonly associated with difficulties in mobility. However, given the lack of clarity on the causal relationship between anxiety and depression and pain, as suggested by Gureje (2007), I cannot say whether respondents reported pain because of a mobility problem or a mobility problem because of generalized pain.

Much of the research on idioms of distress (Gureje 2007; Gureje et al. 2007; Kirmayer & Sartorius 2007) focus on the link between these idioms, expressed in culturally different ways but signifying similar things, and medical conditions, and when medical conditions are not found, to symptoms such as pain, anxiety and depression. Changes in one's body function, stressful events or strong emotions all generate bodily sensations that can be interpreted as illness, and, if these are not resolved, they may be amplified and aggravated by the mediation of other factors (Kirmayer & Sartorius 2007). Living in a context such as I described for Agincourt, is an example of such mediating factors that may aggravate or compound stress.

Idioms of distress are not simple instances of common or more serious mental health disorders, but reflect a holistic reaction to one's life context, and relate to other notions I have discussed earlier of healthworlds (Germond & Cochrane 2010) and homeostatically protected mood (Cummins 2010). Disruption in a person's sense of physical, mental and spiritual wholeness, or an inability to meet one's basic requirements for sustainability, may generate anxiety and depression. Such disruptions were strongly featured in the narratives of many of the ten respondents, and, in less detail, by the 69 respondents described in chapters 5 and 6 respectively.

7.3.3 Disability, wellbeing and health

The discussion in the preceding paragraph links succinctly to the relationship between disability, wellbeing and health. In Chapter 2 I discussed the close relationship between disability, wellbeing and health, and showed that health is a basic requirement for wellbeing, and that wellbeing is about satisfaction, happiness, living a good life, and a person's welfare and quality of life (Easterlin 2003). I list different types of wellbeing, including material wellbeing, health wellbeing, mental wellbeing, emotional wellbeing and spiritual wellbeing (Manderson 2005). If a person's life context does not provide the necessary material, physical, emotional and spiritual elements that ensure overall wellbeing, respondents will express this in ways that are accessible to them. Asking them questions on feeling domains seems to generate such an opportunity.

7.3.4 Conclusion on the meaning of feeling domain statistics

From this discussion, I propose that the meaning of statistics on feeling domains is broad, and reflects to some extent overall wellbeing, and expressed in a health-related framework, as pain, fatigue, anxiety and depression. The causes of these feelings are related to problems in the different elements that make up wellbeing, such as limited basic resources and feeling insecure. Using such measures could provide an additional source of information for measuring population wellbeing.

Thus, the commonly cited increase in the prevalence of common mental health disorders (Lund et al 2010; Lund et al. 2011; Miranda & Patel 2005; Patel et al. 2001), needs to be carefully reviewed with reference to the measures used, and apply this understanding to planning interventions to address this increase. This is especially important when using simple measures in self-report surveys. It is not enough to merely ask the questions without understanding the performance of the questions and the range of potential interpretations lurking in the survey data.

While none of the respondents from the Agincourt interviews reported using medication for anxiety or depression, many recognized areas of turmoil in their lives, and hence reported difficulties in those domains. It is possible that some of these difficulties could be diagnosed clinically as anxiety or depression if assessed more fully. However, given that all the respondents were living at home and were all functionally independent, except those with severe impairments (e.g. respondent 43 with a stroke), it is more likely that the majority were reporting mild forms of common mental health disorders or common 'socioeconomic' disorders. Nevertheless, these could become more significant and clinically diagnosable mental health conditions with persisting hardship, and potentially fragile sustainability of livelihoods. The importance of using more detailed questions, as was done in the World Mental Health Survey (Kessler, Angermeyer, Anthony, De Graaf, Demyttenaere, Gasquet et al. 2007) most likely enhances the ability to differentiate more clearly between clinical and non-clinical responses on these measures, but they remain self-reported measures.

In the above discussion, I have tried to contextualize the importance of understanding what is being measured when interpreting statistics from self-report surveys. My lack of knowledge and experience in the field of mental health limits my ability to delve into this in more depth. Nevertheless, the results from my evaluation of the feeling domain questions reported in chapters 5 and 6, signals some important considerations to be noted in interpreting statistics for these domains. We need to ensure that we are not using simplistic measures that are so broad in their scope that we miss the point of counting such difficulties. On the other hand, the growing literature, as I have described above, reflects a real concern in the need to address these difficulties, and more especially within a broad framework of wellbeing. This requires much more work before we can be comfortable in understanding measures of feeling domains in self-report surveys.

7.4 Understanding disability

A major theme of my findings is that the understanding of disability by the focus groups participants and Agincourt respondents is very different to the theorized understanding of disability as set out by the ICF (WHO 2001), as I discuss in Chapter 2. The participants and respondents' perspective remains within the ambit of 'them, disabled people' versus 'us, not disabled', relegating disabled people to a small marginalized group within society, or some may argue, outside of society. The ICF's (WHO 2001) notion of disability as universal and about everyone is clearly not a dominant view among the population of rural and urban South Africa. Yet participants and respondents reported difficulties. The inclusive nature of the measures evaluated confirms this universal nature of disability. This suggests that there is an important difference between activity limitations a person may have, and the identity of 'disabled'.

The inclusive nature of the WG Short and Extended Sets and the SAGE questions is such that the people counted in as 'disabled' includes both those who do and do not identify as disabled. Those who identify as disabled are a sub group of all people with activity limitations. Very few people who identify as disabled do not report activity limitations. The very few adults (1.52%), who identified as disabled but had no difficulties on the WG Short Set as tested in the StatsSA survey (StatsSA 2006; Schneider et al 2009), further attests to this. Of interest would be to see if these people do report difficulties when answering the WG Extended Set or the SAGE basic activity and feeling domain questions.[53] Although, given that few people with feeling domain difficulties identified as disabled, this may not be the case.

[53] Other possible reasons for 1.52% of StatsSA respondents saying yes to being disabled but no difficulties are as follows: a response error, effective use of assistive devices to manage the difficulty, their difficulty is not reflected in the six domains of the WG Short Set, or they have some form of disfigurement or Albinism which may have no associated activity limitations. People with Albinism, for example, experience significant stigma and strongly identify as disabled (Braathen & Ingstadt 2006).

The contrast between the lay sense of disability and the ICF's definition of disability is something that increasing visibility of statistics on disability could address. But as I say above, this would be only one in a number of interventions. The CRPD's Preamble (UN 2006: 2) describes disability as 'an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others,' What is clear in this description is that disability is about the interaction between impairments and environmental factors, but what is not clear is the nature of the impairment. More specifically, does the CRPD include people with mild basic activity and feeling domain difficulties a person with impairments, or does it only refer to the severe disability end of the continuum? Does the CRPD include as part of its target group, the additional people who are counted into the statistics, but do not identify as 'disabled'? The origins of the CRPD lie in the discrimination, disadvantage and marginalization of disabled people who are understood as being different and not part of 'us normal'. The language of the ICF and CRPD is very similar but it is not entirely clear whether they are referring to the same group of people. The lack of clarity could be related to the different disciplines and groups that led to the ICF and the CRPD. The ICF was developed by the WHO as the ICIDH in 1980 followed by the ICF in 2001. The use of the ICF is strong in the area of rehabilitation and describing population health (as is the case in the SAGE and the WHS). The CRPD arose very firmly out of the Disability Rights Movement and the fight for the equalization of opportunities for disabled people. The inclusive nature of the measures may be too inclusive to suit the purposes of the CRPD. But I discuss that further below in the section on measuring functional status and identity.

While the points I raise above on the understanding are pertinent, they are not within the ambit of what I can answer from the findings of my study. However, what I can show is that there is little

correspondence between the views on disability expressed by my respondents and those embodied in the ICF.

The suggestion arising from this is that one should have two separatemeasures – one for functional status and one for identity status. In this thesis, I have addressed functional status measures, but not identity measures. Nevertheless, if valid measures of disability identity are developed, the benefits would be significant. Analyses of the relationship between the two measures can provide evidence on the type of functional profiles and the severity (on a scale of severity or between two discrete severity categories) that engender an identity as disabled. What type of difficulties and how severe must these be before a person is perceived and treated as 'disabled'? Such evidence can be used for ensuring that services and interventions address the relevant aspects of disability, and particularly discrimination and marginalization. I discuss the functional status and identity measures in more detail below.

The high endorsement of the feeling domains, as discussed above, conforms with the ICF's definition of disability as encompassing more than physical and sensory impairments, but raises the question as to the strictly health-related definition of disability that I refer to in chapters 1 and 2. These feeling difficulties were not associated with being disabled, as few respondents who reported difficulties with these domains, also identified as disabled. The evaluation of these questions highlights that the range of interpretations are wide and reflect different potential causal pathways.

In summary, the results from my thesis confirm, firstly, the close relationship between basic domain difficulties and identifying as disabled, and, secondly, that disability is about more than the marginalized group of people often referred to as 'the disabled' as a way to identify this group as an 'other' or 'them' versus 'us' by people who do not identify as disabled. My results also show that the domains of mental health functioning, measured as feeling domains, are important to measure but are not associated with

the disabled identity, as almost no respondents with such difficulties identified as disabled. Furthermore, these difficulties seem to arise from causes other than an underlying health problem. Many respondents described feeling difficulties arising from their difficult life contexts, although the measures are not able to specify the causal pathways in anyway. Lastly, there is a dissonance between the understanding of disability of respondents as lay people in the field of disability studies, and the theorized understanding of disability, and a lack of clarity between the target group of the CRPD relative to that of the ICF.

7.5 Measuring functional status and identity

The results from my study show that there is a difference between measures of functional status and identity markers, as noted above. The questions in the WG Short and Extended Sets and the SAGE measure functional status, while a question such as 'Are you disabled?' seems to measure identity, although I did not specifically aim to test this and, thus remain tentative in my conclusion. Functional status measures provide information on the level of functioning of a population sampled in a self-report survey. This is not a measure of satisfaction with this level of functioning, nor is it the same as what would be measured in an objective manner. However, measures of all three of these perspectives would provide a comprehensive set of data on a population's functioning. Self-report surveys are, nevertheless, the most economical way of collecting population level information.

Identifying oneself as 'disabled' is not the same as reporting on one's level of functioning. There is a relationship between the two measures, but what constitutes this relationship is not clear or consistent. This is evident for the respondents who reported difficulty on the WG Short Set, but not on the Census 2001 and 'Are you disabled?' questions, and those on the StatsSA survey (StatsSA 2006) who reported 'yes' to having a 'serious disability' (Census 2001 question) but only 'some difficulty' on the WG Short Set, as discussed in Chapter 4.

A‘disabled’ identity stems from appearing or functioning differently, and where these differences are perceived and understood as markers for stigma and disadvantage. Identity is ‘a politically motivated, socio-emotional need… as a response to the forces that oppress and repress the disabled’ (Laclave 2005: 140). It is about not fitting into one’s world or being a ‘misfit’ (Garland-Thomson, 2011). The aim of any disability focused intervention is to create a better fit or generate a more fitting world. Disabled people are, thus, acknowledged as human beings but without full personhood, as set out by Ikäheimo (2009). Personhood is achieved or bestowed when one is seen as worthy of ‘respect, love and contributive valuing’ (Ikäheimo 2009: 80). Full personhood is what allows us into the ‘us’ rather than being relegated to the ‘them’ category, as discussed above. A disabled person was described, by a number of respondents and focus group participants, as someone who cannot do anything for themselves and needing help or, not worthy of contributive valuing (Ikäheimo 2009). The identity as ‘us’ presented by disabled people reflects, what I understand to be a basic premise of a rights or advocacy movement – the identity of the oppressed group must be clearly set in order to highlight and advocate against the oppression. This identity creates an ‘us out of the mainstream’ or ‘us disabled’ group. And this is, in my opinion, one of the major differences between measuring functional status and identity. These measures are not mutually exclusive, but rather work together in making disability more visible and providing accurate and valid evidence for monitoring the status of disabled people. Good measures of identity can highlight experiences of people with more severe difficulties, and provide a means to investigate the extent to which this identity is static, reflecting the traditional view of disability as a small marginalized group of people, or a more fluid and dynamic identity, reflecting a more inclusive understanding of disability, embodied in the measures based on the ICF, including the WG Short and Extended Sets, and the SAGE questions that I evaluated in this thesis.

The long history of disability as an aberration or abnormality in a 'normal world' (Miles 1995; Baynton 2001), exposes the firm foundations of this identity and its related stigmatization. Kudlick (2003) describes this as 'a category that in essence is commonplace, even seen as natural, yet treated as inherently abnormal. Thus [the] very ambiguity and changing meanings [of disability] open up uncharted areas of research and modes of analysis, which in turn will bring about a greater understanding of disability and its repercussions.' Baynton (2001: 51) describes this ongoing stigmatization effectively with his example of pregnant women being given access to parking for disabled people:

> A recent proposal [circa 1999 – 2001] in Louisiana to permit pregnant women to use parking spaces reserved for people with mobility impairments was opposed by women's organizations. A lobbyist for the Women's Health Foundation said, "We've spent a long time trying to dispel the myth that pregnancy is a disability, for obvious reasons of discrimination." She added, "I have no problem with it being a courtesy, but not when a legislative mandate provides for pregnancy in the same way as for disabled persons."To be associated with disabled people or with the accommodations accorded disabled people is stigmatizing.

Inclusive measures asking about difficulty walking, for example, will draw attention to the large number of people who could benefit from accessible parking. The reasons for the difficulty in walking is not important, and will include, amongst others, older people who have less energy, people with spinal cord injuries who are unable to walk, blind people who require an assistant to find their way around a place, and women who are pregnant and struggling to walk for long distances. However, if these accommodations remain within the realm of perceived 'disability accommodations', the reaction described by Baynton above, will challenge the provision of such accommodations. Thus, we need to consider carefully what the benefits are of using such measures. A more positive consequence of using

these measures, could be a shifting of perceptions, as I discussed earlier in relation to expanding the category of 'us'.

7.6 Comprehensive measurement of disability

As I have explained, disability measurement, to be fully comprehensive, must include measures of all the different components of disability, including complex activity domains, the impact of environmental factors on basic and complex activities, and the environmental factors themselves, as set out in the ICF (WHO 2001). These are all components that measure the level of difficulty a person has, and the impact of environmental barriers and facilitators. Work on these other aspects is moving ahead. For example, the WG is starting work on measurement of participation and environmental factors in surveys. Gray and his colleagues have developed a subjective measure of environmental barriers and facilitators (Gray, Hollingsworth, Stark & Morgan 2008), and Whiteneck and his colleagues have developed the Craig Hospital Inventory of Environmental Factors – the CHIEF (Whiteneck, Harrison-Felix, Mellick et al. 2004). The work undertaken by the latter two groups were not intended for use in surveys, but the CHIEF, has been used but not properly analysed, in at least two surveys – the Zambian Living Conditions Survey (SINTEF 2006) and the Tanzania Disability Survey (Tanzania National Bureau of Statistics 2010).

Further work on developing measures for these other ICF components will benefit from the work conducted on developing and testing questions on basic activities and feeling domains. The other areas of wellbeing, such as satisfaction, happiness and quality of life, are separate from measurement of disability itself (Cieza et al 2008), and I do not address measurement of these here, except to note that the methodology used are applicable to develop measures for these aspects of wellbeing.

7.7 Chapter conclusions

From the results of my study, I can conclude that the measures evaluated in this study are valid and transparent for all domains, although revisions are required in the Shangaan translation of the questions on cognition (remembering and concentration), and a betterunderstanding developed on the different causes of difficulties on non-traditional or feeling domains. While these are good measures, the translation of using these measures into improved conditions for people with such difficulties remains elusive. The strong showcasing of disability as 'inability' and as a negatively stereotyped feature of being human, perpetuates the need, I argue, to retain a strong notion of a 'disabled' identity, and to develop good measures of this identity. This requirement is for the disabled person to claim his or her rights.

My thesis can only go as far as highlighting the difference between measures of functional status and identity, and provide evidence on the performance of current measures of functional status. I do not provide evidence of what is a good measure of identity, nor go further than mere hypothesis building on the impact of better functional status measures on increasing the integration of traditionally marginalized disabled people.

Furthermore, the different ways in which the traditional basic activity domains are endorsed compared to that of the non-traditional or feeling domains, highlights the differences between identifying as disabled or not. Disability, for the respondents in my study, is about traditional domains, while non-traditional domains are not about disability, according to these respondents. These latter domains are about expressing difficulties in maintaining homeostasis in one's mood,as described by Cummins (2010), and not about being 'unable to do things'.

Chapter 8

Conclusions

This thesis is located within the field of self-report survey methodology, and specifically on disability measurement. As I set out in Chapter 1, statistical error in survey data arises from a number of sources, including respondents – the focus of this thesis. The aim of my thesis was to evaluate existing measures of disability, with specific reference to the role of wording, question understanding and interpretation, and people's life context in determining their responses to questions on functioning. The added value of my thesis to the work on question evaluation at an international level relates to: a) the documentation of the difference between 'difficulty' and 'disability'; b) the confirmation of the universality of many responses to the measures of basic activity (seeing, hearing, mobility, self care and cognition); and, c) the raising of some interesting contextual nuances in the interpretation of measures of cognition (language influence) and the feeling domains (socio-economic and geographic influences). In Chapter 2, I summarized the relevant literature on disability and its measurement, touching on some of important related concepts, such as wellbeing and health. These related concepts provide useful perspectives that assist in explaining responses obtained from the respondents, but remain a secondary rather than main focus of my thesis. In Chapter 3, I set out how I conducted the study. In Chapters 4, 5 and 6, I set out the analysis and results for the role of wording, question understanding and interpretation, and life context factors, in determining respondents' approaches and responses to the disability questions. In Chapter 7, I integrate these findings and set out some key implications of these in relation to moving the field of disability measurement forward and understanding disability. In this concluding chapter, I set out what my thesis contributes to our knowledge on disability measurement, and the implications of this for a range of sectors within and outside of government. While my work is focused on South Africa and, in

part, on a rural area within South Africa, the findings add to a growing pool of information at an international level on disability measurement and survey methodology.

Having explored the social life of a questionnaire, I conclude that the effect of wording is important, as asking about difficulties people have results in a more inclusive and transparent measure than asking about disability. The WG Short Set, WG Extended Set and SAGE questions are valid (within the confines of the validity testing I conducted), while questions such as the South African Census 2001 question is not. These measures of difficulty on basic activities and feeling domains are, in the majority, correctly understood and interpreted, and provide better information than that obtained on traditional and categorical measures of disability. No information is lost, as all people who are counted in by the traditional, categorical measures are also counted in with difficulties on basic activities questions. The transparency of the measures is a key feature, as this is what allows data users to understand the potential sources of error in the data and to take these into account when inferring from the data.

While being based in part within the WG/UNESCAP study, my study was a more detailed exploration, and on a smaller sample, of different factors that determine how people respond to questions on disability. The detailed analysis of the ten cognitive testing interviews was more than what was possible for the 150 interviews in the WG/UNESCAP study. The effect of wording and the role of life context factors were not addressed in the WG/UNESCAP study. My thesis thus provides a more holistic and detailed view of how respondents interpret and respond to questions, than was possible on the WG/UNESCAP study. Nevertheless, the results of my study add to the work of the WG (Madans, Loeb & Altman 2011), UNESCAP (2010), and the Budapest Initiative (Madans et al. 2011). These initiatives provide a solid evidence base for effectively measuring disability.

As I have explained, disability measurement, to be fully comprehensive, must include measures of all the different components of disability, including complex activity domains, the impact of environmental factors on basic and complex activities, and the environmental factors themselves, as set out in the ICF (WHO 2001). These are all components that measure the level of difficulty a person has, and the impact of environmental barriers and facilitators. In summary, the effective measurement of disability requires the following steps:

- Application of the inclusive and transparent measure of basic activities and feeling domains on any and all survey platforms, including censuses (using the WG Short Set for reason of questionnaire space), and surveys of health, labour force participation, general household living conditions, income and expenditure, and any other similar and commonly run surveys in most countries, including South Africa.
- Mainstreaming the analysis of findings from these measures, in a similar way that gender, geographical location and age are mainstreamed in such survey analyses
- Applying these results to effective policy development and monitoring and evaluation.

As measures of the other components of disability are developed, these can be added to these surveys. While many of these surveys are national in scope, the application of the same principles remains valid for population based surveys at provincial and local level. Hence, the AHPU and StatsSA can benefit from applying similar methods of question evaluation for any surveys they undertake, and more especially for surveys that show unexplained results or that use questions that are new and untested. In summary, the steps required for undertaking question evaluation prior to piloting any survey instrument include the following:

- Draft questions based on the most current understanding of the relevant construct, and select those that are new or have produced difficult to interpret survey results on other surveys.
- Conduct a series of cognitive testing interviews (Miller & Willson 2009) with about ten to twenty people from the target population, focusing on those with lower education and socio-economic status. The questions being evaluated are asked, the respondent answers and this is followed by a seris of probes to elicit the story behind the response; for example: What was the respondent thinking about? Why did he or she answer in this way?
- Transcribe and analyze these interviews to determine the congruence of the respondents' interpretations of the question intent and descriptions provided of why they answered in this way.
- Differences and similarities between the respondents will indicate the severity of any problems and revisions to the questions are required.
- Focus groups can also be conducted where respondents answer the questions prior to starting the discussion, and the facilitated discussion focuses on the meaning of the questions and how people understood them.

Mainstreaming of disability across a range of different data collection platforms will enhance the visibility of disability, in the same way that gendered analyses have highlighted the difference in experiences of women and men. This would provide an ongoing source of accessible data for monitoring functional status in relation to health, wellbeing and quality of life, and provide a rich source of data for reporting on the implementation of the UN's CRPD. This is a requirement for all countries that have ratified the CRPD, including South Africa. Furthermore, the desired outcome of using these inclusive and transparent measures is better information for planning policies and services, as well as eventually,

together with other interventions, a change of attitudes towards people with disabilities, where their abilities are as evident as their disabilities.

This thesis, as a context specific case study (i.e. South Africa, and primarily a rural area of South Africa), adds to an evidence base on disability measurement, by exploring and highlighting important shifts in the field. The first shift is from categorical measures ('deaf, blind, crippled') to measures that generate profiles of functioning. This has important implications for a shift in understanding disability as 'unable to do anything', with a focus on one impairment, to a profile of functioning, ranging from full functioning to full disability for different domains.

The second shift is from exclusive to inclusive measures. The traditional and categorical measures are about excluding potential members of the category, usually where a person has an impairment that is not extreme in severity, such as partially hearing and not deaf, or partially sighted but not blind, as shown primarily in Chapter 4. The numbers of people with the most severe disabilities are usually small, and can easily be ignored or provided with limited resources.[54] Furthermore, excluding people with less severe difficulties denies them the right to advocate for services that are accessible and that meet their specific impairment needs: for example, elderly people with mobility difficulties who can benefit from accessible transport; or partially sighted people who benefit from adequate lighting and adapted computer software. The measures of difficulty coupled with the scaled response options are more inclusive of people with less severe difficulties, while also including people with severe and extreme difficulties. The potential danger is the over-inclusion of people with milder difficulties, the implications of which are not yet apparent in my findings or in the work of the WG and WHO.

[54] However, the strict categorical limits are useful for creating a sense of identity, as, for example, the Deaf community have done in asking for recognition as a different language group than a disability group.

The last but related shift is from measures that are opaque to ones that are transparent. The 'disability' focused questions (e.g. the Census 2001 question), at face value, seem clear in what they are measuring. But, as I have shown in this thesis, a closer investigation underscores the lack of clarity in what is being measured. Neither severity nor identity are effectively measured, as shown above and in preceding chapters. In contrast, the measures of difficulty are clear and transparent in what they are measuring, beyond face value. People interpreted the questions correctly, except for the question on remembering and concentrating, and provided responses that corresponded to the examples and descriptions they gave of their difficulties. Their understanding and interpretations were congruent with the intended meaning.

These measures are correctly understood and interpreted, but they count in as 'disabled' people who report problems not obviously health related, but, from the respondents' narratives, appear to be related more to socioeconomic conditions, or socioeconomically-related. These are people who report difficulties with anxiety, depression, fatigue, sleep and pain, as a reaction, it seems, to living in contexts of adversity and hardship, such as in Agincourt. This is a potential problem when considering the meaning of the statistics generated by these questions. My findings do not suggest any clear solutions on how to manage this problem, beyond asking more than one question and looking at the combined responses across these extended questions. It is clear, from the respondents' narratives, that living with adversity and hardship generates feelings of anxiety, depression, and probably fatigue and pain. What is not clear is the difference between such reported difficulties and clinically diagnosable mental health disorders, or whether there is a continuum between these two – reporting difficulties because of hardship, and developing a clinically diagnosable mental health disorder through continued exposure to such conditions. We need to understand in more depth statements such as 'poverty is disabling'.

8.1 Policy implications

The need for accurate and cross country comparable measures of disability has increased with the ratification of the UNCRPD by 110 countries as of early 2012.[55] Ratification compels countries to report on the implementation of the CRPD on a regular and ongoing basis, as alluded to above. One of the major reporting components is data describing the lives and experiences of disabled persons relative to those of non-disabled persons. In order to report such data, good measures of disability are required, rather than the narrowly focused traditional categorical measures. As I discuss in Chapter 7, we lack clarity on what should be reported on to capture the experiences of disabled people. Do we include the experiences of people, such as the Agincourt respondents who reported problems in the feeling domains? The answer to this question requires ongoing work in analysing existing data, developing literacy of disability statistics, and setting out clearly what are the parameters of the target population of the CRPD, while acknowledging that the evolving nature of disability would require fluid and dynamic parameters for this population.

The use of transparent and inclusive measures of disability will generate clearer and more valid statistics, providing a good evidence base for policy development. Mainstreaming of these measures will also shift policy makers to acknowledge and take into considerations the needs of people with difficulties, as the numbers will increase and, hence, be more visible. This is the same as gendered analyses of survey data making the different experiences of men and women more visible to policy makers. Some reactions of countries, when faced with an increase in number of 'disabled people', is negative as the implications are that more resources are required. Developing a good understanding of

[55] See UNCRPD website at www.un.org/disabilities accessed on 20 February 2012.

what these statistics mean would alleviate some of this negativity. Not all people with mobility difficulties require wheelchairs, but all could benefit from accessible transport and buildings.

Currently services for people with disabilities tend to be provided according to impairments – for example, schools for the Deaf, schools for the Blind, and services for people with physically disabilites. This categorization is also reflected in the organisations for and of disabled people; for example, the National Council for the Blind, Deaf Federation of South Africa, and the National Council for Persons with Physical Disabilities of South Africa. The use of measures that do not categorize people may require a shift in how services are provided. Although beyond the scope of this thesis, further exploration and careful monitoring over time, using these inclusive and transparent measures, will be needed to see if this transition is necessary and how it can be facilitated. My thesis provides the building blocks of measurement to start this process.

The role of improved disability measures is crucial in any public health programme. With the transition in health from high mortality to increased long-term infectious and non-communicable diseases (Mayosi et al. 2009; Tollman et al. 2007), the functional consequences of living with such health problems must be documented, as was the case in the AHPU's adult health module using the SAGE questions. Measures of functional status should be monitored together with clinical markers to provide an holistic picture of the benefits of health interventions, as is suggested in the description of health status by the Task Force on Health Status (2005a) referenced in Chapter 2.

8.2 Limitations of my study

Coming to the end of a study such as the one reported in this thesis, generates much reflection on how it could have been conducted more effectively. In this section, I present some of these reflections.

My study aimed to evaluate existing measures of disability. I did this by selecting question sets that were similar in the wording of questions, and the domains of functioning covered. I did not focus on exploring the differences between these question sets as such, but rather focused on their similarities. A number of features of the performance of these question sets[56] were noted but not developed in any depth. This included issues such as translation issues (beyond the issue related to cognition), and use of time references in framing the questions (e.g. last 30 days vs no mention of time periods). These issues require further investigation of their effect in determining people's responses. These are all areas that should be explored in their own right.

The staggered timing of the different data collection phases meant that the questions used were not fully matched in the different phases (e.g. WG Short Set, WG Extended Set and SAGE questions). Ideally, a further study would compare the SAGE and WG Extended Set questions and undertake cognitive interview testing of the whole SAGE set of questions, beyond the basic activity ones included in this study. The assumption was made that the WG Short Set and Extended sets were sufficiently similar in structure and underlying theoretical framework that they could be used interchangeably. While the results of my study did show a good measure of overlap, there were some differences that emerged as discussed in Chapter 6. Further research should compare the severity and type profiles elicited from a larger sample of respondents on the WG Extended set to those I describe for the SAGE in Chapter 6. If the profiles emerging are the same or very similar to the SAGE profiles, this would confirm the similarities between these two sets of questions.

[56] I use the term questions or question set and not survey instruments or questionnaires, as these questions can be used as independent modules or as part of a wider set of disability measures, and are not likely to comprise a whole survey instruments in themselves.

The techniques used for generating the functioning profiles, in Chapter 6, used a simple method of scaling of responses. Different analyses could be applied, including, for example, different categorization of the total functioning scores, to determine whether this yields different profiles, and different conclusions.

The open-ended questions posed in the semi-structured interviews in Agincourt, such as on economic and social resources, and life satisfaction, were very limited and produced inadequate information for a comprehensive description. A stronger data base investigating these issues would have used either more detailed sets of questions, such as a quality of life measure, or more in-depth qualitative interviews. The data I collected allowed for limited analysis of the association between these and the functioning profiles.

The original idea I had for the Agincourt data collection was to use in-depth qualitative interviews on how people understood their functioning, with a small sample of respondents. For a number of reasons, I shifted the focus to semi-structured interviews for the 69 respondents and returned to the more in-depth cognitive testing interview method for the final ten interviews. Conducting in-depth interviews requires skill and a good knowledge of the language of the interview. While I have experience in conducting such interviews, I can only do this effectively in English. The selection of a rural area with Shangaan speakers necessitated the use of local research assistants, who were fluent in Shangaan, but lacked experience in in-depth interviewing. As my experience has taught me, it takes time to train a person to be a good qualitative interviewer, and it was not feasible to conduct such extensive interviews. As a result I changed the focus to use a larger sample and conduct semi-structured interviews. On reading the interview transcripts once all the 69 semi-structured interviews had been completed, it became apparent that the interview guide was too structured and did not facilitate probing by the research assistants when an interesting response was given. For research assistants to be

fully conversant in how to conduct detailed and in-depth qualitative interviews requires time and skills development. This was not possible within the time frame of my data collection phases. The trade off was to develop a questionnaire that proved to be too structured and did not facilitate the elicitation of more detailed narratives. Because of not being fully immersed and familiar with the research question, the research assistants missed opportunities to delve further into the topic. With more time and resources, I could have undertaken a longer period of training with the research assistants and conducted more piloting of the semi-structured component of the interview.

Given these limitations related to the 69 semi-structured interviews, I decided to use a different approach for the final ten interviews. I conducted these interviews with the assistance of Shangaan speaker who had some experience and skill in interpreting. While this gave me much more control over the interview process and space to probe when relevant, it did create a stilted interview, at times, due to the language barriers and time taken to translate responses into English and translate my further questions into Shangaan.

The problems raisedwith the measurement of the feeling domains, and specifically those of anxiety, depression and fatigue, were raised above. While I am able to evaluate the performance of these measures and note the problems raised, I am not able to provide a fully coherent interpretation of what the implications are. This requires further work by researchers more familiar with the field of mental health in order to deepen our understanding of the meaning of the statistics generated by these questions, and answer the question 'In what sense is poverty disabling?'

There are some pertinent themes that are relevant to the ICF and to the South African context which I have not addressed. These are the measurement of activity limitations with and without the use of

assistive devices, and the role of the social assistance grant (the Disability Grant) in determining people's responses to the questions.

With regard to the use of assistive devices, the context of Agincourt was such that assistive devices were not easily available, and hence few respondents used any. There were references made in a few instances to using a walking stick or glasses but these were limited, and to the geographical environment of long distances. This gap should be addressed more formally in further research.

The disability grant is a non-contributory cash transfer paid to people who qualify because of being poor and disabled (de Koker et al 2006). The uptake is good and the amount paid provides a regular amount that is often higher than basic casual labourer wages. The knowledge of this grant may have pushed people to answer positively as having difficulties. Only one person mentioned the Disability grant as an issue for her as she wanted to qualify but did not, as she had chronic illnesses but no moderate to severe activity limitations, as required for eligibility.[57] Other respondents mentioned receiving other social assistance grants. In short, the Disability Grant did not emerge as a reason for reporting difficulties on the questions I evaluated, but the issue could be looked at in more detail in future studies.

8.3 Moving forward in disability measurement

To collect data for this thesis, I used small samples of purposively selected respondents, and from one rural area in South Africa for the larger part of the study (Agincourt). The findings contribute to our knowledge of how these measures perform, but we need to expand the evaluation process to more areas within South Africa, and include field testing on population based samples of respondents, before we can conclude finally on the validity of the measures for use in South Africa. This was done in part for

[57] I headed the team that developed the assessment tool and criteria for eligibility for the Disability Grant.

the WG Short Set by the survey conducted by StatsSA in 2006 following the focus group study (Schneider & Couper 2006).

I have focused on subjective self-report measures of disability, which were found to be well understood, except for the question on cognition (remembering and concentrating). Further studies should compare the level of functioning measured for the same person using these self-report measures together with objective assessments. Evidence provided by such studies would allow for further understanding of the relationship between subjective and objective measures of functional status.

Many countries still retain the use of the traditional categorical measures of disability, but a number of countries are shifting to using measures such as the WG Short Set and the WHO Disability Assessment Schedule (WHO-DAS II). Typically, in my experience in a number of countries, [58] governments and disability organisations want to know how many people are, for example, blind, deaf or physically disabled, in order to plan for the provision of relevant services appropriate infrastructure (e.g. access to water, sanitation, roads), and assistive devices. They refer to the traditional categorical measures as a way to collect this information. Given the lack of validity of these measures, we need to develop an analytical strategy that allows the same information to be gleaned from the more inclusive and transparent measures. The research question would focus on whether the response codes 'a lot of difficulty' and 'unable to do', or 'severe and extreme difficulties' for SAGE questions, provide the necessary information. Further research would investigate the functional status profiles generated by these measures for people with known illnesses or impairments.

[58] I am a member of the WG and was appointed as a consultant on the WG/UNESCAP project. I have undertaken consultancies on various aspects of disability measurement in Uganda, Zambia, Fiji and South Africa.

I raised a concern about the potentially over-inclusive nature of the WG and SAGE measures, and the danger of this diluting or masking the disadvantage experienced by people with severe difficulties. In order to avoid this, good analytical guidelines should be provided on using different cutoff points. This type of analysis would show, for example, the level of severity or type of domain difficulty that would generate an identity of 'different' and 'out of the mainstream'; or, in other words, that is perceived as different from 'normal' and discriminated against on the basis of this difference. This would inform interventions to reduce stigma and related discrimination.

The findings underscore the need for education on how to use the statistics generated by these measures. My thesis has confirmed, using data from South Africa, that there is no single statistic, and any statistic needs to be understood in relation to the measures used and analysis applied to the data. This point applies to any statistic, and not only to disability statistics.

The focus on measures of basic activities and feeling domains was determined by the status of disability measures currently, and the role of these domains in generating difficulties in more complex domains. Further work, similar to what I did in this thesis, needs to be done on measures of the other elements of disability, including complex domains of activity, participation, and environmental factors as the major components of disability as set out in the ICF (WHO 2001). Following this development, more analysis on the role of basic activities in underpinning more complex activities can be undertaken. This work is still in its infancy internationally and should continue. In addition, the use of questions for children and by proxy respondents for adults needs to be investigated.

The difference between functional status and disability identity must be addressed by developing measures of disability identity to complement those for functional status.

Finally, in this thesis I focused on question evaluation and understanding the potential sources of data error generated by respondents in a self-report survey context. The methods used in this study are not relevant only for disability measurement, but have relevance for any measures used in any self-report survey. This thesis provides an example of how this can be done.

Baynton, in his seminal essay on how disability is used in justifying inequalities, comments that disability is everywhere, if you just know how to look for it, and, because of this, 'it is time to bring disability from the margins to the center of historical enquiry' (2001: 52). In a similar vein, I conclude my thesis by stating that these valid disability measures need to be brought into the centre of all data collection platforms and, with this shift, we will see that disability is everywhere. We will know how to measure and 'find' disability in an inclusive and transparent manner. My thesis contributes ways to look for disability by evaluating what happens when a survey questionnaire starts its social life, but continuing research in this area is warranted and needed.

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Appendix 1: WG Short Set, Census 2001 and 'Are you disabled?' questions used in the focus group discussions.

(Only the sections used in the analysis for this thesis are included)

Questionnaire on functioning questions for Census 2011: Adults

1. **Are you disabled?** a) Yes b) No
   - If yes, please state what your disability is or disabilities are.

2. Census 2001

Do you have any serious disability that prevents your full participation in life activities (such as education, work, social life)? *MARK ANY THAT APPLY.*

8. None
9. Sight
10. Hearing
11. Communication
12. Physical
13. Intellectual
14. Emotional

3. Washington Group Short Set

The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM					
		No	**Yes**		
		No difficulty	**Some difficulty**	**A lot difficulty**	**Unable to do**
1.	Do you have difficulty seeing, even if wearing your glasses?	1	2	3	4
2.	Do you have difficulty hearing, even if using your hearing aid?	1	2	3	4
3.	Do you have difficulty walking or climbing steps?	1	2	3	4
4.	Do you have difficulty remembering or concentrating?	1	2	3	4
5.	Do you have difficulty with self-care, such as washing all over or dressing?	1	2	3	4
6.	Because of a physical, mental, or emotional health condition, do you have difficulty communicating, (for example understanding or being understood by others)?	1	2	3	4

Appendix 2: Washington Group Extended Set questions used in cognitive testing interviews with Shangaan translation.

I will begin with some background questions.

RECORD SEX AS OBSERVED	Female Male	1 2
How old are you now?	____ years ___ years	
1. How many years in all did you spend <u>studying in school</u>, college or university? *Xana uni malmbe malngani hinkwawo lawa unga maendla exikolweni kumbe xikolo xa lehenhla?*		
2. What is the highest level of schooling or post-schooling that you have completed? Hi yihi nthangha ya lehenhla leyi u ngayi pasa exikolweni kumbe dyondzo ya lenhla leyi unga yi heta?	_____ (Put in country specific levels of education)	

3. In your own words, can you tell me about your training or education? (You can ask whatever question or questions that are necessary for you to understand the kind of training and education that the respondent has had in their lifetime).

Hi marito ya wean, ndzi hlamuseli hi swa tidyondzo ta wean ta le henhla

What is your <u>current marital status</u>? ***(SELECT THE SINGLE BEST OPTION)*** *Hi xihi xiyimo xa wean xa vukati*	Never married *A ndzi catanga*	1
	Currently married *Ndzi catini*	2
	Separated *Hi hambanini*	3
	Divorced	4
	Widowed *Muferiwa*	5
	Cohabiting *Ndzi tshama ninga lovoriwanga*	6

Which describes your main work status best? (select the single best option) *Hi xihi xi hlamuselaka xiyimo xa ntirho wa wean kahle*	Paid work *Ntirho wo hakela*	1
	Self employed, such as own your business or farming *Kutitirha, ku fana ni ku va ni bindzu kumbe purasi*	2
	Non paid work, such as volunteer or charity *Ntirho lowu nga hakeleki kufana ni kutinyikela*	3
	Student *Mudyonzi*	4
	Keeping house/Homemaker *Mulanguteri wa lendwlini*	5
	Retired *Muhori wa pencini/ awa ha tirhi*	6
	Unemployed (health reasons) *A wutirhi (hikwalaho ka mavabyi)*	7
	Unemployed (other reasons) *A wutirhi(hikwalaho ka swivangelo swinwana)*	8
	Other (specify) *Swi nwanyana (Hlamusela)* _____	9

4. In your own words, can you tell me about what you do for a living? (You can ask whatever question or questions that are necessary for you to understand how the respondent spends their time, makes an earning, or is supported).

Hi marito ya wena, ni byeli leswi u swiendla ku va uti hanyisa?

1. VISION	
Questions	**Response Options**
SS1a: Do you have difficulty seeing, even when wearing glasses? *Xana una ku tikeriwa ku vona loko us ambale tinghilazi to vona ha tona?*	1) no difficulty – *EE* 2) some difficulty - 3) a lot of difficulty 4) Cannot do at all/ unable to do
1.1a Do you wear glasses to see far away? *Xana u ambala tinghilazi ku vona ekule?* 1.1b. Do you wear glasses to see up close? *Xana u ambala tinghilazi ku vona ekusuhi?* 1.1c. Do you wear glasses for another reason? (*other*): _____ *Xana u ambala tinghilazi hi swivangelo swin'wana ke?*	1) Yes 2) No *If **Yes**, read **glasses** in **room** question.* 1) Yes 2) No *If **Yes**, read **glasses** in **coin** question.* 1) Yes 2) No *If **Yes**, record other.*
1.3 Do you have difficulty clearly seeing someone's face across a room [***even when wearing your glasses***]? *Xana u na kutikeriwa ka ku vona kahle xikandza xa munhu unwana langa etlhelo rinwana ra kamara ke?*	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/ unable to do *If **No**, go to 1.4.*
11.1ai How old were you when the difficulty seeing far away began? *A wuri malembe mangani loko u sungula ku tikeriwa ku vona kule?*	_____age in years
12.1i Is your difficulty seeing far away due to a health problem or something else? *Xana ku tikeriwa ka wena ka ku vona kule kunga va ku vangiwa hi swiphiqo swa rihanyo ra wena kumbe swinwana ke?*	1) Due to a health problem 2) Something else: _____

13.1i Does your difficulty seeing far away limit your ability to carry out daily activities? *Ku tikeriwa ka wena ka ku vona ekule swingava swi ku pimela kaku endla mintirho/migingiriko ya wena ya masiku hinkwawo?*	1) Yes 2) No
13.2bi Does your difficulty seeing far away limit your ability to carry out other activities that are not part of your day-to-day life? *Ku tikeriwa ka wena kaku vona ekule swingava swi ku pimela kaku endla migingiriko ya wena leyi ngariki ni xiavi eka vutomi bya siku na siku?*	1) Yes 2) No
1.4 Do you have difficulty clearly seeing the picture on a coin [***even when wearing your glasses***]? *Xana u ni kutikeriwa eka ku vona kahle xifaniso ehenhla ka mali ya nsimbi ke? [niloko u ambale swo pfuneta ku vona]*	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/ unable to do *If **No**, go to <u>next section</u>.*
11.1ai How old were you when the difficulty seeing close up began? *A wuri na malembe mangani loko u sungula ku tikeriwa kaku vona swilo ekusuhi?*	_____ age in years
12.1i Is your difficulty seeing close up due to a health problem or something else? *Ku tikeriwa ka wena kaku vona swa lekusuhi swingava swiendliwa hi swiphiqo swa rihanyo kumbe swinwana ke?*	1) Due to a health problem 2) Something else: _____
13.1i Does your difficulty seeing close up limit your ability to carry out daily activities? *Ku tikeriwa ka wena kaku vona ekusuhi swinga swiku pimela eka kuendla migingiriko ya masiku hinkwawo*	1) Yes 2) No

13.2bi Does your difficulty seeing close up limit your ability to carry out other activities that are not part of your day-to-day life? *Ku tikeriwa ka wena ka ku vona ekusuhi swinga swiku pimela eka kuendla migingiriko yinwana leyi ngariki ni xiavi eka vutomi bya siku na siku?*	1) Yes 2) No

2. HEARING

Questions	Response Options
SS2: Do you have difficulty hearing, even if using a hearing aid? *Xana una kutikeriwa ku twa, hambi u tirhisa swo pfuneta ku twA?*	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/ unable to do
2.1 Do you use a hearing aid? *Xana wa turhisa swopfuneta ku twa?* 2.2 **If yes:** How often do you use your hearing aid(s)? *Loko u pfumela: xana u tirhisa kangani swo pfuneta kutwa?*	1) Yes 2) No *If **Yes**, read **hearing aid** in **noisy room** and **quiet room**.* 1) All of the time 2) Some of the time 3) Rarely 4) Never
2.3 Do you have difficulty hearing what is said in a conversation with one other person in a noisy room [***even when wearing your hearing aid(s)***]? *Xana u na ku tikeriwa kutwa loko u vulavula na munhu un'wana eka endlwini leyi ngana huwa hambi utirhise[ni loko u ambale swopfuneta kutwa]?*	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/ unable to do *If **No difficulty**, go to <u>next section</u>.*

2.4 Do you have difficulty hearing what is said in a conversation with one other person in a quiet room [***even when wearing your hearing aid(s)***]? *Xana uni kutikeriwa eka kutwa loko u vulavurisana ni munhu u nwana eka kamara leri nga miyela [ni loko u ambale swopfuneta kutwa/?*	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/ unable to do
11.1i How old were you when the difficulty hearing began? *A wuri ni malembe mangani loko u sungula kutikeriwa eka kutwa?*	_____ age in years
12.1i Is your difficulty hearing due to a health problem or something else? *Ku tikeriwa ka wena eka kutwa swingava swi vangiwe hi swiphiqo swa rihanyo kumbe swinwana ke?*	1) Due to a health problem 2) Something else: _____
13.1i Does your difficulty hearing limit your ability to carry out daily activities? *Ku tikeriwa ka wena ka kutwa swingava swiku pimela kuendla migingiriko/mintirho ya masiku hinkwawo?*	1) Yes 2) No
13.2bi Does your difficulty hearing limit your ability to carry out other activities that are not part of your day-to-day life? *Ku tikeriwa ka wena ka kutwa singava swiku pimela kuendla migingiriko yinwana leyi ngariki ni xiavi eka vutomi bya siku na siku?*	1) Yes 2) No

3. MOBILITY

Questions	Response Options
SS3. Do you have any difficulty walking or climbing steps?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/ unable to do
3.1a Do you use any equipment or receive help for getting around?	1) Yes

Xana u tirhisa switirhisiwa kumbe u kuma mpfuneto eka ku famba famba/ku jikajika? 3.2 **If Yes:** Do you use any of the following? *Loko u pfumela: Xana wa tirhisa swinwana swa leswi landzeleka?* a. cane or walking stick? *Nhonga yo famba ho yona?* b. walker? (Zimmer frame) c. crutches? *Tinhonga* d. wheelchair? *Xigholonyani xa vatsoniwa* e. prosthesis(es)? *Milenge yo vekeleriwa* f. someone's assistance? *Mpfuneto wa munhu unwana* g. other? (specify: _____) *Swinwanyana (Hlamusela:_____)* 3.3 **If more than one:** Which [aid/assistance] do you use most often? *Loko swihundza xinwe: Hi xihi(xo pfuneta ku famba) lexi uxi tirhisaka swinene?*	2) No If **no** go to 3.4 1) Yes 2) No 1) Yes 2) No 1) Yes 2) No 1) Yes 2) No 1) Yes 2) No 1) Yes 2) No 1) Yes 2) No Specify aid from a-g list: _____ ***Insert **most used aid** in the following questions*.
3.4 Do you have difficulty walking 100 (metres) on level ground, that would be about (*insert country-specific example*) [***without the use of your*** **[insert aid]**]?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/ unable to do *If **Cannot do at all**, go to 3.6 -- stairs question*.
3.5 Do you have difficulty walking 500 (meters/yards) on level ground, that would be about (*insert country-specific example*) [***without the use of your*** **[insert aid]**]?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/ unable to do

3.6 Do you have difficulty walking up or down [*insert country-specific example*: a flight of stairs / 12 steps / a small hill] [***without the use of your*** **[insert aid]**]? Xana uni kutikeriwa kaku famba u ya henhla nile hansi [*nyika xikombiso xo kongoma*: ku khandziya swi tepisi kumbe xintshabyana] [inga tirhisanga [hoax xo pfuneta]	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/ unable to do
************EXPERIMENT************** **For first 10 interviews:** 3.7 Do you have difficulty walking around in your home [***without the use of your*** **[insert aid]**]? Xana uni kutikeriwa eka ku famba/ ku jikajika ekaya [unga tirhisanga [hoax swopfuneta] **For second 10 interviews:** 3.7a In the last 30 days, how much difficulty did you have in moving around inside your home? [***without the use of your*** **[insert aid]**]? Eka masiku ya makume-nharhu lamanga hundza, u veni kutikeriwa ka njhani eka ku famba famba endzeni ka ndyangu? [e handle ka ku tirhisa [hoxa xopfuneta]?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/ unable to do 1) None 2) Mild 3) Moderate 4) Severe 5) Extreme/Cannot Do *If* ***no aid****, go to next section*.
Only if respondent uses an aid: 3.8 Do you have difficulty walking 100 (meters/yards) on level ground, that would be about (*insert country-specific example*), even when using your**[insert aid]**]? Xana uni kutikeriwa eka ku famba dzana ra tikhilomitara eka rivala ra ripala, leswi nga endlaka (ni ka xikombiso xo	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/ unable to do

kongoma) ni loko uri karhi unga tirhisanga [hoxa swopfuneta]	*If **Cannot do at all**, <u>go to 3.10 – stairs question</u>*.
3.9 Do you have difficulty walking 500 (meters/yards) on level ground, that would be about (*insert country-specific example*), even when using your**[insert aid]**]? Xana uni kutikeriwa eka ku famba ntlhanu wa madzhana ra tikhilomitara eka rivala ra ripala, leswi nga endlaka (nika xikombisa xo kongoma) ni loko u ri karhi unga tirhisi [hoxa swopfuneta]	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/ unable to do
11.1ai How old were you when the difficulty walking began? A wuri ni malembe mangani liko u sungula ku tikeriwa eka ku famba?	_____ age in years
12.1i Is your difficulty walking due to a health problem or something else? Ku tikeriwa ka wena ka ku famba swinga va swiendliwa hi swiphiqo swa rihanyo kumbe swinwana?	1) Due to a health problem 2) Something else: _____
13.1i Does your difficulty walking limit your ability to carry out daily activities? Ku tikeriwa ka wena ka ku famba swingava ni swipimelo eka kuendla mintirho ya masiku hinkwawo?	1) Yes 2) No
13.2bi Does your difficulty walking limit your ability to carry out other activities that are not part of your day-to-day life? Ku tikeriwa ka wena eka ku famba swingava ni swipimelo eka ku endla mintirho leyi ngariki ni xiavi eka vutomi bya siku na siku?	1) Yes 2) No

3.10 Do you have difficulty walking up or down [*insert country-specific example*: a flight of stairs / 12 steps / a small hill], even when using your**[insert aid]**]? Ku tikeriwa ka wena eka ku famba uya henhla na le hansi [nyika xikombiso xokongoma: ku khandziya switepisi	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/ unable to do
******EXPERIMENT********** **For first 10 interviews:** 3.11 Do you have difficulty walking around in your home, even when using your**[insert aid]**]? Xana una ku tikeriwa ku famba ekaya ra wena, na loko u tirhisa [hoxa swipfuneto] **For second 10 interviews:** 3.11a In the last 30 days, how much difficulty did you have in moving around inside your home, even when using your**[insert aid]**]? Eka masiku ya makume-nharhu lamanga hundza, u veni kutikeriwa ka njhani eka ku famba famba endzeni ka ndyangu, na loko u tirhisa [hoxa swipfuneto]	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/ unable to do 1) None 2) Mild 3) Moderate 4) Severe 5) Extreme/Cannot Do
11.1ai How old were you when the difficulty walking up or down [*insert country-specific example*: a flight of stairs / 12 steps / a small hill] began? A wuri ni malembe mangani liko u sungula ku tikeriwa eka ku famba uya henhla na le hansi. [nyika xikombiso xokongoma: ku khandziya switepisi	_____ age in years
12.1i Is your difficulty walking up or down [*insert country-specific example*: a flight of stairs / 12 steps / a small hill]	1) Due to a health

due to a health problem or something else? Ku tikeriwa ka wena ka ku famba uya henhla na le hansi swinga va swiendliwa hi swiphiqo swa rihanyo kumbe swinwana?	problem 2) Something else: _____
13.1i Does your difficulty walking up or down [*insert country-specific example*: a flight of stairs / 12 steps / a small hill] limit your ability to carry out daily activities? Ku tikeriwa ka wena ka ku famba uya henhla na le hansi swingava ni swipimelo eka kuendla mintirho ya masiku hinkwawo?	1) Yes 2) No
13.2bi Does your difficulty walking up or down [*insert country-specific example*: a flight of stairs / 12 steps / a small hill] limit your ability to carry out other activities that are not part of your day-to-day life? Ku tikeriwa ka wena eka ku famba uya henhla na le hansi swingava ni swipimelo eka ku endla mintirho leyi ngariki ni xiavi eka vutomi bya siku na siku?	1) Yes 2) No

4. COMMUNICATION

Questions	Response Options
SS4. Using you usual language, do you have difficulty communicating, for example understanding or being understood?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/ unable to do
4.1 Do people have difficulty understanding you when you speak? Xana vanhu va ni ku tikeriwa eka ku twisiswa loko u vulavula?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/ unable to do *If **No**, go to next section*.
4.2 **If Yes:** Do you use any of these forms of communication? 4.3 Loko u phumela: Xana u nga va u tirhisa landzelaka loko u vulavaula?	1) Yes 2) No 1) Yes 2) No

a. sign language? Ririmu ro khombetela b. hand writing? Kutsala hivoko c. typed or text messages? Marito lama nga khandziyiswa d. communication or picture board or cards? Mbulavulo kumbe bodo ya xivafiso e. computer assisted communication device? Xilo xo pfuneta ku vulavula xa pynatu "computer" komphuta f. an interpreter? mhlamuseri g. other? (specify: _____) swiwanyana (hlamusela)	1) Yes 2) No 1) Yes 2) No 1) Yes 2) No 1) Yes 2) No
11.1ai How old were you when the difficulty communicating began? A wuri na malebe ma ngani loko khutikeriwa ka wena ka ku vulavula ku sungula	_____ age in years
12.1i Is your difficulty communicating due to a health problem or something else? Xana kutikeriwa ka wena ka ku vulavula swinga va swiendliwe hi mhaka ya rihanyo kumbe swiwana ke?	1) Due to a health problem 2) Something else: _____
13.1i Does your difficulty communicating limit your ability to carry out daily activities? Xana kutikeriwa ka wena ka ku vulavula swinga va swiku pimela endla mintiro ya masiku hinkwaho	1) Yes 2) No
13.2bi Does your difficulty communicating limit your ability to carry out other activities that are not part of your day-to-day life? Xana kutikeriwa ka wena ka ku vulavula swinga va swiku pimela kuendla mintro leyingarina xiave eka vutomi bya siku na siku	1) Yes 2) No
5. COGNITION (REMEMBERING) – Two Sets	

Questions	Response Options
SS5. Do you have difficulty remembering or concentrating?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/ unable to do
SET A: 5A.1 How often do you have difficulty remembering important things? Ikangani u ngava na ku tikeriw eka ku tsundzuka swa nkoka	1) Never If **Never**, go to 5.C 2) Sometimes 3) Often 4) All of the time
5A.2 Thinking about the last time you had difficulty remembering important things, how much difficulty did you have? Hleketa nkari lowu ngahundza lowu nga va na kutikeriwa eka ku tsundzuka, u ve niku tikeriwa kangani	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/ unable to do
SET B: 5B.2 Do you have difficulty remembering a few things, a lot of things, or almost everything? Xana uni kutikeriwa eka ku tsundzuka swilo swi tsongo, swilo swotala, kumbe hinkwaswo ka swona	1) A few things 2) A lot of things 3) Almost everything
5.3 In the last 30 days, how much difficulty did you have analyzing and finding solutions to problems in day to day life? Eka masiku ya makume mhanarhu lamanga hundza, xana a vena ku tikeriwa	1) None 2) Mild 3) Moderate 4) Severe 5) Extreme/Cannot Do
5.C In the last 30 days, how much difficulty did you have in concentrating on doing something for **ten minutes**?	1) None 2) Mild 3) Moderate 4) Severe 5) Extreme/Cannot Do

11.1ai How old were you when the difficulty remembering or concentrating began? A wuri ni malembe ya ngani loko ku fikeriwa ka wena eka ku tsandzuka ni kutinyiketela	____ age in years
12.1i Is your difficulty remembering or concentrating due to a health problem or something else? Xana ku tikeriwa eka ku tsundzuka na kutiyiketela swinga va swivange hi swiphiqo swa rihanyo kumbe swinwana ke?	1) Due to a health problem 2) Something else: _____
13.1i Does your difficulty remembering or concentrating limit your ability to carry out daily activities? Xana ku tikeriwa eka ku tsundzuka na	1) Yes 2) No
13.2bi Does your difficulty remembering or concentrating limit your ability to carry out other activities that are not part of your day-to-day life?	1) Yes 2) No
6. UPPER BODY	
Questions	**Response Options**
SS6a. Do you have difficulty with self care, such as washing all over or dressing?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/ unable to do
SS6b. Do you have difficulty raising a 2 liter jug of water from waist to eye level? Xana uni tikeriwa eka ku tlakula mati ya mpimo wa tilitara timbirhi kusuka emyongeni kefika ematihlweni?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/ unable to do
6.1 Do you use any aids or equipment or receive help with lifting? Xana u tirhisa switirhisiwa swo karhi swo pfuneta kutlakula?	1) Yes 2) No *If **No**, go to 6.4 – hands and fingers question*.

6.2 **If Yes:** What types of aids, equipment or assistance do you use? Hi swihi switirhisiwa leswi u swi tirhisaka swo ku pfuneta ke tlakula?	Specify all: _____
6.3 **Only if uses aid:** Do you have difficulty raising a 2 liter jug of water from waist to eye level even when using your aid? Xana u ni kutikeriwa eka kutlakula mati ya mpimo wa tilitara timbirhi ni loko u tirhisa swopfuneta?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/ unable to do
11.1ai How old were you when the difficulty lifting began? A wuri ni malembe mangani loko kutikeriwa ka wena ka kutlakula ku sungula?	_____ age in years
12.1i Is your difficulty lifting due to a health problem or something else? Xana kutikeriwa ka wena ka kutlakula swingava swivangiwe hi swiphiqo swa rihanyo kumbe swinwana?	1) Due to a health problem 2) Something else: _____
13.1i Does your difficulty lifting limit your ability to carry out daily activities? Kutikeriwa ka wena ka kutlakula swingava swiku pimela kuendla migingiriko ya masiku hinkwawo?	1) Yes 2) No
13.2bi Does your difficulty lifting limit your ability to carry out other activities that are not part of your day-to-day life? Xana kutikeriwa ka wena ka kutlakula swingava swiku pimela kuendla migingiriko yi nwana leyi ngariki ni xiavi eka vutomi bya siku na siku	1) Yes 2) No
6.4 Do you have difficulty using your hands and fingers, such as picking up small objects, for example, a button or pencil, or opening or closing containers or bottles?	1) no difficulty 2) some difficulty

Xana u ni kutikeriwa eka kutirhisa mavoko na tintiho ta wena, kufana ni kutlakula swilo swintsongo, xikombiso, bateni kumbe xitsalo, kumbe kupfula ni kupfala khonteni kumbe bhodlele	3) a lot of difficulty 4) Cannot do at all/ unable to do *If N**o**, go to <u>next section</u>.*
6.5 Do you use any aids or equipment or receive help when using your hands or fingers? Xana u tirhisa swopfuneta swokarhi kumbe switirhisiwa kumbe u kuma mpfuneto loko u tirhisa mavoko ya wena kumbe tintiho? 6.6 What types of aids, equipment or assistance do you use? Hi swihi swimpfuneto, switirhisiwa kumbe mpfuno lowu u wu tirhisaka?	1) Yes 2) No *If **Yes**, read aidin **next question**.*
11.1ai How old were you when the difficulty using your hands or fingers began? A wu rini malembe mangani loko kutikeriwa ka wena ka kutirhisa mavoko ni tintiho ta wena swi sungula?	_____ age in years
12.1i Is your difficulty using your hands or fingers due to a health problem or something else? Kutikeriwa ka wena eka ku tirhisa mavoko na tintiho swinga va swiendliwa hi swiphiqo swa rihanyo kumbe swinwana?	1) Due to a health problem 2) Something else: _____
13.1i Does your difficulty using your hands or fingers limit your ability to carry out daily activities? Xana kutikeriwa ka wena ka ku tirhisa mavoko ni tintiho ta wena swingava swi kupimela eka kuendla migingiriko ya masiku hinkwawo?	1) Yes 2) No
13.2bi Does your difficulty using your hands or fingers limit your ability to carry out other activities that are not part of	1) Yes

your day-to-day life? Xana kutikeriwa ka wena eka ku tirhisa mavoko ni tintiho ta wena swingava swi kupimela eka kuendla migingiriko leyi ngariki ni xiavi eka vutomi bya siku na siku?	2) No
7. LEARNING	
Questions	**Response Options**
7.1 Do you have difficulty understanding and using information like following directions to get to a new place? Xana una khutikeriwa eka ku twisisani kutirisa hungu rolerisa ku ya fika eka	1) no difficulty [If **NO**, go to <u>next section]</u> 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/ unable to do
7.2a Do you have difficulty learning new things such as the rules for a new game? Xana una kutikeriwa eka kudyondza swilko swintshwa tani hi minihilawu ya untlangu wu ntshwa?	1) no difficulty 2) some difficulty 3) a lot of difficulty 4) Cannot do at all/ unable to do
7.2b In the last 30 days, how much difficulty did you have in analyzing and finding solutions to problems in day to day life?	1) None 2) Mild 3) Moderate 4) Severe 5) Extreme/Cannot do
11.1ai How old were you when the difficulty understanding and using information began? Awuri ni malebe mangani loko kutikeriwa kawena kaku twisisa ni ku tirihisa hungu kusungula?	_____ age in years
12.1i Is your difficulty understanding and using information due to a health problem or something else? Xana kutikeriwa ka wena ka ku twisisa ni kutirjisa hungu, swingave swiendla hi swiphilo swa hungu kumbe swiwana ke?	1) Due to a health problem 2) Something else: _____

13.1i Does your difficulty understanding and using information limit your ability to carry out daily activities? Xana kutikeriwa ka wena ka kutwisisa ni kuthirisa hungu, swinga va ni mpimelo eka kuendla migingiriko ya masiku hinkwawo?	1) Yes 2) No
13.2bi Does your difficulty understanding and using information limit your ability to carry out other activities that are not part of your day-to-day life? Xana kutikeriwa ka wena ka kutwisisa ni ku tirhisa hungu swinga va ni mpimelo eka kuendla migingiriko leyingariki ni xiavi eka vutomi bya siku na siku	1) Yes 2) No

8. AFFECT (ANXIETY AND DEPRESSION)

Questions	Response Options
8.1a How often do you feel worried, nervous or anxious? Daily, Weekly, Monthly, A few times a year, or Never? Ikhangani u ti twa ko u vani kuvilela, kutshava, kumbe riphalo, masiku hinkwaho, vhiki rinwana na rinwana, nhweti yinwana na yinwana, minkarhi nyana yitsongo a lembeni kumbe ku hava?	1) Daily 2) Weekly 3) Monthly 4) A few times a year 5) Never *If N**ever**, go to 8.5 -- depression question*.
8.2 Do you take medication for anxiety? Xana wa teka mimirhi ya ripfalo?	1) Yes 2) No
8.3 Thinking about the last time you felt anxious, how would you describe the level of anxiety? Mild, moderate or severe? Hlekata hi rama hetelelo u twa ripfalo, enga ku ari ri njani.	1) Mild 2) Moderate 3) Severe
8.4 Thinking about the last time you felt anxious, was the anxiety worse than usual, better than usual, or about the same as usual? Hleketa nkarhi wo hetelela loko u va ni loko u titwa uri ni ripfala, ripfalo ra wena ariri ngopfu kutlula ntolovelo, ariantswa kutlula ntolovelo, kumbe aswilava kuringana	1) Worse than usual 2) About the same as usual 3) Better than usual

ni ntolovelo?	
11.1ai How old were you when the anxiety began? A wuri ni malembe mangani loko u sungula kuva ni ripfalo?	_____ age in years
12.1i Is your anxiety due to a health problem or something else? Ripfalo ra wena ringava riendliwe hi swipiqo swa rihanyo kumbe swinwana?	1) Due to a health problem 2) Something else: _____
13.1i Does your anxiety limit your ability to carry out daily activities? Xana ripfalo ra wena ringava riku pimela eka ku endla migingiriko ya masiku hinkwawo?	1) Yes 2) No
13.2bi Does your anxiety limit your ability to carry out other activities that are not part of your day-to-day life? Xana ripfalo ra wena ringava riku pimela eka kuendla migingiriko leyi ngariki ni xiavi eka vutomi bya siku na siku?	1) Yes 2) No
8.5 How often do you feel depressed? Daily, weekly, monthly, a few times a year, or never? I kangani laha u titwaka moya wa wena wu rihansi? Masiku hinkwawo, vhiki an vhiki, nhweti na nhweti, ka ntsongo a lembeni, kumbe kuhava?	1) Daily 2) Weekly 3) Monthly 4) A few times a year 5) Never *If **Never**, go to next section*.
8.6 Do you take medication for depression? Xana wa teka/kutirhisa mimirhi ya loko moya wa wena wu ri hansi?	1) Yes 2) No
8.7 Thinking about the last time you felt depressed, how depressed did you feel, a little, a lot, or somewhere in between a little and a lot? Hleketa ro hetelela loko u titwa moya wa wena wuri hansi, moya wa wena a wuri hansi njhani, switsongo, swinene, kumbe exikarhi ka switsongo ni swinene?	1) A little 2) A lot 3) Somewhere in between a little and a lot

8.7b **If somewhere in between:** Would you say the depression was closer to a little, closer to a lot, or exactly in the middle? Unga vula leswaku moya wa wena wu le kusuhi ni switsongo, kusuhi na swinene, kumbe a xikarhi?	1) Closer to a little 2) Closer to a lot 3) Exactly in the middle
8.8 Thinking about the last time you felt depressed, was the depression worse than usual, better than usual, or about the same as usual? Hleketa ro hetelela loko moya wa wena wu ehansi, moya wa wena a wuri hansi swinene kutlula ntolovelo, aswi antswa kutlula ntolovelo, kumbe aswilava kuringana ni ntolovelo?	1) Worse than usual 2) About the same as usua1 3) Better than usual
11.1ai How old were you when the depression began? A wu rini malembe mangani loko moya wa wena wu sungula kuva hansi?	_____ age in years
12.1i Is your depression due to a health problem or something else? Ku va moya wa wena wu va hansi swingava swiendliwa hi swiphiqo swa rihanyo kumbe swinwana?	1) Due to a health problem 2) Something else: _____
13.1i Does your depression limit your ability to carry out daily activities? Xana kuva moya wa wena wuri ehansi swinga va swiku pimela kuendla migingiriko ya masiku hinkwawo?	1) Yes 2) No
13.2bi Does your depression limit your ability to carry out other activities that are not part of your day-to-day life? Kuva moya wa wena wuri ehansi swingava swiku pimela kuendla migingiriko yi nwana leyi ngariki ni xiavi eka vutomi bya siku na siku?	1) Yes 2) No
9. PAIN	
Questions	**Response Options**

9.1a Do you have frequent pain? Xana utshama uri ni swivavi?	1) Yes 2) No
9.2 Do you use medication for pain? Xana u tirihisa mimirhi eka swivavi swa wena?	1) Yes 2) No *If **No** to **both questions**, go to next section*.
9.3 **If yes:** In the past 3 months, how often did you have pain? Some days, most days, or every day? Loko u pfumela: eka tinhweti tinharhu leti nga hundza, I kangani laha ungava ni swivavi? Masiku manwana, masiku yo tala, kumbe masiku hinkwawo?	1) Some days 2) Most days 3) Every day
9.4 Thinking about the last time you had pain, how long did the pain last? Some of the day, most of the day, or all of the day? Hleketa ro hetelela loko uri ni swivavi, nkarhi nyana wa siku, nkarhi wo leha wa siku, kumbe siku hinkwawo?	1) Some of the day 2) Most of the day 3) All of the day
9.5a Thinking about the last time you had pain, how much pain did you have, a little, a lot, or somewhere in between a little and a lot? Hleketa ro hetelela loko uri ni swivavi, uve ni kuvava ka njhani, swintsongo, swinene, kumbe xikarhi ka switsongo na swinene? 9.5bb **If somewhere in between:** Would you say the amount of pain was closer to a little, closer to a lot, or exactly in the middle? Loko kuri xikarhi: unga vula leswaku nhlayo ya swivavi swa wena a yi ri kusuhi na switsongo, kusuhi na swinene, kumbe exikarhi?	1) A little 2) A lot 3) Somewhere in between a little and a lot 1) Closer to a little 2) Closer to a lot 3) Exactly in the middle
9.6 Thinking about the last time you had pain, was the pain worse than usual, better than usual, or about the same as usual? Hleketa ro hetelela loko uri ni swivavi, aswi vava ngopfu kutululula ntolovelo, answi antswa kutlula ntolovelo,	1) Worse than usual 2) About the same as usua1 3) Better than usual

kumbe a swifana ni ntolovelo?	
9.7 How would you describe your pain? Xana unga swi hlamusela njhani swivavi swa wena?	
11.1ai How old were you when the pain began? A wuri ni malembe mangani loko swivavi leswi swi sungula?	_____ age in years
12.1i Is your pain due to a health problem or something else? Xana swivavi leswi swingava swivangiwe hi swiphiqo swa rihanyo kumbe hi swinwana?	1) Due to a health problem 2) Something else: _____
13.1i Does your pain limit your ability to carry out daily activities? Swivavi leswi swingava swiku pimela kuendla migingiriko ya masiku hinkwawo?	1) Yes 2) No
13.2bi Does your pain limit your ability to carry out other activities that are not part of your day-to-day life? Swivavi leswi swingava swiku pimela kuendla gingiriko leyi ngariki ni xiavi eka vutomi bya siku na siku?	1) Yes 2) No

10. FATIGUE

Questions	Response Options
10.1a Do you have frequent feelings of being tired? Xana utshama irikarhi u titwa u karhele?	1) Yes 2) No *If **No**, go to next section*.
10.2 In the past 3 months, how often did you feel tired? Some days, most days, or every day? Eka tinhweti tinharhu leti nga hundza, I kangani laha unga titwa u karhele?	1) Some days 2) Most days 3) Every day
10.3 Thinking about the last time you felt tired, how long did the tiredness last? Some of the day, most of the day, or all of the day? Hleketa ro hetelela loko u titwa u karhele, ku karhala ka	1) Some of the day 2) Most of the day 3) All of the day

wena kuteke nkarhi wo leha kufika kwihi? Nkarhi nyana wa siku, nkarhi wo leha wa siku, kumbe siku hinkwaro?	
10.4 Thinking about the last time you felt tired, how would you describe the level of tiredness? Mild, moderate or severe? Hleketa ro hetelela loko utitwa u karhele, xana unga hlamusela njhani xiyimo xa ku karhala? Kahle, xikarhi kumbe ngopfu?	1) Mild 2) Moderate 3) Severe
10.5 Thinking about the last time you felt tired, was the tiredness worse than usual, better than usual, or about the same as usual? Hleketa ro hetelela loko u titwa u karhele, ku karhala ka wena a kuri ngopfu kutlula ntolovelo, a swi antswa kutlula ntolovelo, kumbe a swifana na ntolovelo?	1) Worse than usual 2) About the same as usua1 3) Better than usual
11.1ai How old were you when the tiredness began? A wuri ni malembe mangani loko ku karhala ka wena kusungula?	_____ age in years
12.1i Is your tiredness due to a health problem or something else? Ku karhala ka wena swingava swi endliwa ha swiphiqo swa rihanyo kumbe swina?	1) Due to a health problem 2) Something else: _____
13.1i Does your tiredness limit your ability to carry out daily activities? Xana ku karhala ka wena swingava swiku pimela kuendla migingiriko ya masiku hinkwawo?	1) Yes 2) No
13.2bi Does your tiredness limit your ability to carry out other activities that are not part of your day-to-day life? Xana ku karhala ya wena swingava swiku pimela kuendla migingiriko yi nwana leyi ngariki ni xiavi eka vutomi bya siku na siku?	1) Yes 2) No

Appendix 3: Definitions applied for selection of respondent for semi-structured interviews

- Criteria 1: responses to questions in 2006 Census SAGE (Short Version) for the following Questions on Adult health module: QIQ1002, QIQ1004, QIQ1010, QIQ1015, QIQ1018, QIQ1023, QIQ1024, QIQ1026, QIQ1027, QIQ1032 to give 5 groups for selection:
    - 1 - No difficulty = no difficulty (code 1) on all Qs or a maximum of mild (code 2) responses on any two questions.
    - 2 - Mild Difficulty = mild difficulty (code 2) for at least 3 Qs.
    - 3 – Moderate Difficulty = moderate difficulty (code 3) on at least 2 Qs.
    - 4 – Severe difficulty = severe difficulty (code 4) on at least 1 Q.
    - 5 - Extreme difficulty = extreme difficulty (code 5) on at least 1 Q.
- Criteria 2: sex with even distribution as far as possible of males and females
- Criteria 3: age with categories 18 – 49 yrs and 50 + yrs
- Criteria 4: SES by low and high
- Successful interview where the result code (on the respondent data entry) indicated a completed interview at the time of the census data collection in 2006.
- Residence = living in the village for a while and likely to be remaining (coded as at $\geq$ 12 for residence on the census 2006 data)

Appendix 4a) : SAGE questionnaire adapted for 69 semi-structured interviews

Name: _____

Agincourt ID: _____

Sex: **male** ☐ **Female** ☐

Age: _____

Date of Interview: _____

Address and Village: _____

Interviewer: _____

Section 1: Short set of functioning questions

Do you have difficulty in doing any of the following because of a health condition	**No difficulty** EE	**Some difficulty** Nkarhi wu n'wana	**A lot of difficulty** Ko tala	**Unable to do** A swi koteki
1. **Seeing (with glasses if you wear them)** Ku vona loko u ambale swopfuneta ku vona (tinghilazi)	1	2	3	4
2. Hearing (with a hearing aid if you wear one) Ku twa loko u tirhisa swo pfuneta ku twa	1	2	3	4
3. Walking a kilometre or climbing a flight of steps Ku famba mpfhuka wo ringana kilomitara kumbe ku khandziya switepisi leswi nga talanyana	1	2	3	4
4. remembering Ku tsundzuka swilo	1	2	3	4
5. Concentrating Ku tinyiketela ku endla swilo	1	2	3	4
6. . With self-care, such as washing all over or dressing Hi ku tihlayisa, ku fana na ku tihlambisa na ku tiambexa	1	2	3	4
7. In communicating in your usual language, including sign language (i.e. understanding others or being understood by others) Ku vulavula hi ririmi ra masiku hinkwawo (Xikombiso, ku twisisa kumbe ku twisisiwa hi van'wana)	1	2	3	4

Section 2: SAGE Short set of questions

Now we will switch to questions specifically about your health. The first questions are about your overall health, including both your physical and your mental health. By difficulty in the second question, I mean requiring increased effort, discomfort or pain, slowness or changes in the way you do the activity.

Sweswi hi ta nghena ka swivutiso leswi kongomaneke ni rihanyu ra wena. Swivutiso swo sungula swi angarhela rihanyu ra wena hinkwaro ku katsa rihanyu ra miri na ra miehleketo ya wena.

Q2000	***In general, how would you <u>rate your health today</u>?*** *Hi ntolovelo, unga vula leswaku xiyimo xa wena xa rihanyu xi njhani namunthla?*	*1* *2* *3* *4* *5*	*Very good* *Good* *Moderate* *Bad* *Very bad*
Q2001	***Overall in the last 30 days, how much difficulty did you have with <u>work or household activities</u>?*** *Hi ku katsakanya ka masiku ya makume-nharhu lama nga hundza,I ku tikeriwa ka njhani loku u nga va na kona hi ntirho kumbe hi mintirho yi n'wana ya laha kaya?*	*1* *2* *3* *4* *5*	*None* *Mild* *Moderate* *Severe* *Extreme/cannot do*

Now I would like to review the different functions of your body. When answering these questions, I would like you to think about the last 30 days, taking both good and bad days into account. When I ask about difficulty, I would like you to consider how much difficulty you have had, on average, in the last 30 days, while doing the activity in the way that you usually do it. Let me remind you, by difficulty I mean requiring increased effort, discomfort or pain, slowness or changes in the way you do the activity.

Sweswi ndzi lava ku humesela handle ku hambana ka ku tirha ka miri wa wena.Loko u hlamula swivutiso leswi, ndzi lava u ehleketa hi masiku ya makume-nharhu lama nga hundza. U tsundzuka swa kahle ni swo kala swi nga ri kahle. Loko ndzi vutisa hi ku tikeriwa ndzi lava u tekela enhlokweni ku I ku tikeriwa ka njhani loko unga va na kona ka masiku ya 30 lawa ya nga hundza Loko uri ku endleni ka leswi u toloveleke ku swi endla. Leswi lavaka u engetela matimba , u twa ku vava, u nonoka u nga endli hi ndlela leyi u toloveleke ha yona.

INTERVIEWER: Read and show scale to respondent.

MOBILITY

Overall in the last 30 days,how much difficulty did you have … *Hi ku angarela ka masiku ya makume nharhu lama nga hundza u ve na ku tikeriwa ka njhani*	***NONE*** ***KU HAVA***	***MILD*** ***KAHLE***	***MODERATE*** ***XIKARHI***	***SEVERE*** ***NGOPFU***	***EXTREME / CANNOT DO*** ***NGOPFU-NGOPFU/U NGE KOTI KU ENDLA***

Q2002	*… with moving around?* *Hi ku famba famba?*	*1*	*2*	*3*	*4*	*5*

SELF-CARE

	Overall in the last 30 days,how much difficulty did you have … *Hi ku angarela ka masiku ya makume nharhu lama nga hundza u ve na ku tikeriwa ka njhani*	***NONE*** ***KU HAVA***	***MILD*** ***KAHLE***	***MODERATE*** ***XIKARHI***	***SEVERE*** ***NGOPFU***	***EXTREME / CANNOT DO*** ***NGOPFU-NGOPFU/U NGE KOTI KU ENDLA***
Q2004	***… with self-care, such as bathing/washing or dressing yourself?*** ***Hi ku tihlayisa,ku fana na ku tihlambisa/ku hlantswa kumbe ku tiambarisa/ambexa?***	*1*	*2*	*3*	*4*	*5*

PAIN AND DISCOMFORT

	Overall in the last 30 days… *Hi ku angarela ka masiku ya makume nharhu lama nga hundza*	***NONE*** ***KU HAVA***	***MILD*** ***KAHLE***	***MODERATE*** ***XIKARHI***	***SEVERE*** ***NGOPFU***	***EXTREME / CANNOT DO*** ***NGOPFU-NGOPFU/U NGE KOTI KU ENDLA***
Q2007	*…how much of bodily aches or pains did you have?* *U vile na ku vava ka miri na switlavi swo fika kwihi?*	*1*	*2*	*3*	*4*	*5*
	If Q2007 = 1, "None"……..…. ➔ *Q2010*					
Q2009	*… how much difficulty did you have in your daily life because of your pain?* *U vile na ku tikeriwa ko fika kwihi ka vutomi bya wena bya siku rin'wana na rin'wana hikuva u ri na switlavi?*	***1***	***2***	***3***	***4***	***5***

COGNITION

	Overall in the last 30 days, how much difficulty… *Hi ku katsakanya/angarela ka masiku ya makume-nharhu lama nga hundza, u vile naku tikeriwa ka njhani…*	***NONE*** ***KU HAVA***	***MILD*** ***KAHLE***	***MODERATE*** ***XIKARHI***	***SEVERE*** ***NGOPFU***	***EXTREME / CANNOT DO*** ***NGOPFU-NGOPFU/U NGE KOTI KU ENDLA***
Q2010	*… did you have with concentrating or remembering things?* *Ka ku tinyiketela na ku tsundzuka swilo?*	*1*	*2*	*3*	*4*	*5*

Q2011	*… did you have in learning a new task (for example, learning how to get to a new place, learning a new game, learning a new recipe)?* *Ka kudyondza tirho wuntswa (xikombiso, ku dyondza ku ya eka tindhawu letintswa, ku dyondza mitlango yintswa, ku dyondza ta maswekelo letintswa)?*	*1*	*2*	*3*	*4*	*5*

INTERPERSONAL ACTIVITIES

Overall in the last 30 days, how much difficulty… *Hi ku katsakanya/angarela ka masiku ya makume-nharhu lama nga hundza, u vile naku tikeriwa ka njhani…*		***NONE*** ***KU HAVA***	***MILD*** ***KAHLE***	***MODERATE*** ***XIKARHI***	***SEVERE*** ***NGOPFU***	***EXTREME / CANNOT DO*** ***NGOPFU-NGOPFU/U NGE KOTI KU ENDLA***
Q2012	*… with personal relationships or participation in the community?* *Hi vuxaka bya wena bya lexihundleni kumbe ku teka xiphemu eka swa vaaka tiko?*	*1*	*2*	*3*	*4*	*5*
Q2014	*… with making new friendships or maintaining current friendships?* *Ku endla vunghana lebyintswa kumbe ku hlayisa vunghana lebyi u nga na byona sweswi?*	***1***	***2***	***3***	***4***	***5***
Q2015	*…with dealing with strangers?* *Ku tirhana na swita swifamba?*	***1***	***2***	***3***	***4***	***5***

SLEEP AND ENERGY

Overall in the last 30 days, how much of a problem did you… *Hi ku angarela eka masiku ya makume-nharhu lama nga hundza, I xiphiqo xihi lexi unga va na xona.*		***NONE*** ***KU HAVA***	***MILD*** ***KAHLE***	***MODERATE*** ***XIKARHI***	***SEVERE*** ***NGOPFU***	***EXTREME / CANNOT DO*** ***NGOPFU-NGOPFU/U NGE KOTI KU ENDLA***
Q2016	***… have with sleeping, such as fallingasleep, waking up frequently during the night or waking up too early in the morning?*** ***Hi ku etlela, kufana na kuva u khomi hi vurhongo, ku va na nkelunkelu, kumbe ku va u pfuka ka ha ri mixo swinene?***	*1*	*2*	*3*	*4*	*5*

AFFECT

Overall in the last 30 days, how much of a problem did you have… *Hi ku angarela eka masiku ya makume-nharhu lama nga hundza, I xiphiqo xihi lexi unga va na xona.*		***NONE*** ***KU HAVA***	***MILD*** ***KAHLE***	***MODERATE*** ***XIKARHI***	***SEVERE*** ***NGOPFU***	***EXTREME / CANNOT DO*** ***NGOPFU-NGOPFU/U NGE KOTI KU ENDLA***
Q2018	*…with <u>feeling sad, low or depressed</u>?* *Hi ku titwa u nga tsakanga,u ri hansi,kumbe u ri na tsikelelo?*	*1*	*2*	*3*	*4*	*5*
Q2019	*… with <u>worry or anxiety</u>?* *Hi ku vilela kumbe ku navela?*	*1*	*2*	*3*	*4*	*5*

VISION***(respondent should answer, as when wearing glasses/contact lenses if used)***

Q2020	*When was the last time you had your <u>eyes</u> examined by a medical professional?* *A ku ri rini ro hetelela loko mahlo ya wena ma nga kamberiwa hi mukamberi wa ntokoto?* INTERVIEWER: ENTER YEARS AGO. ENTER "00" IF LESS THAN 1 YEAR.	☐☐ *YEARS AGO* *-8* DON'T KNOW *98 NEVER*
Q2021	*Do you use eyeglasses or contact lenses to see <u>far away</u> (for example, across the street)?* *U tirhisa tighilazi ta mahlo ku vona kule? (Xikombiso, hi tlhelo leri n'wana ra xitarata?*	*1 YES* *2 NO*
Q2022	*Do you use eyeglasses or contact lenses to see <u>up close</u> (for example at arms length, like when you are reading)?* *U tirhisa maghilazi ya mahlo ku vona swa le ku suhi xikombiso ndhawu ya leha ku ringana na voko ra wena, ku fana na loko u ri ku hlayeni?*	*1 YES* *2 NO*
Q2023	*In the last 30 days, how much difficulty did you have in seeing and recognising an object or a person you know <u>across the road</u> (from a distance of about 20 meters)?* *Ka masiku ya makume-nharhu lama nga hundza, u vile na ku tikeriwa ko fika kwihi eka ku vona na ku va u tiva xan'wa nchumu kumbe munhu loyi u n'wi tivaka loyi anga hala thlelo rin'wana ra patu (ka xivandla xa kwalomu ka makume-mbirhi wa timitara?*	*1 NONE* *2 MILD* *3 MODERATE* *4 SEVERE* *5 EXTREME / CANNOT DO*
Q2024	*In the last 30 days, how much difficulty did you have in seeing and recognising <u>an object at arm's length</u> (for example, reading)?* *Ka masiku ya makume-nharhu lama nga hundza,u vile na ku tikeriwa ko fika kwihi ka ku vona kumbe ku tiva xa nchumu lexi nga kwalomu ka ku leha ka voko(xikombiso,ku hlaya)?*	*1 NONE* *2 MILD* *3 MODERATE* *4 SEVERE* *5 EXTREME / CANNOT DO*

FUNCTIONING ASSESSMENT

These next questions ask about difficulties due to health conditions. Health conditions include diseases or illnesses, other health problems that may be short or long lasting, injuries, mental or emotional problems, and problems with alcohol or drugs.

Swivutiso leswi landzelaka swivutisa hi ku tikeriwa hikokwalaho ka xiyimo xa rihanyu.Xiyimo xa rihanyu xi katsa mavabyi, swiphiqo swin'wana swa rihanyu leswi nga tekaka nkarhi wo koma kumbe nkarhi wo leha, ku vaviseka, swiphiqo swa mihleketo kumbe ku khunguvanyeka, na swiphiqo swa xihoko kumbe swidzidziharisi.

Think back over the last 30 days and answer these questions thinking about how much difficulty you had doing the following activities. Some of these questions may seem repetitive, but we do need your attention and it is important to give us answers to each question.

Hleketa ndzhaku ka masiku ya makume-nharhu lama nga hundza u hlamula swivutiso leswi u hleketa kuri hi kwihi ku tikeriwa loku unga na kona eku endleni ka mintiro leyi landzelaka.Swin'wana swa swivutiso leswi swi nga tikomba swi yelela, kambe hi lava u swi tekela nhlokweni na ku ri i swa nkoka ku hi nyika tinhlamulo eka xivutiso xin'wana na xin'wana.

INTERVIEWER: ***For each question, please circle only one response. 'N/A' means 'not applicable'.***

In the last 30 days, how much difficulty did you have … *Eka masiku ya makume-nharhu lama nga hundza,u vile na ku tikeriwa ko fika kwihi*		***None*** ***Ku hava***	***Mild*** ***Kahle***	***Moderate*** ***Xikarhi***	***Severe*** ***Ngopfu***	***Extreme / cannot do*** ***Ngopfu-ngopfu/u nge koti ku endla***	***N/A***
Q2028	… in standing for long periods? *Ku yima nkarhi wo leha?*	***1***	***2***	***3***	***4***	***5***	***9***
Q2032	… in taking care of your household responsibilities? *Ku va u ri wena loyi a nga yena ahlayisaka muti?*	***1***	***2***	***3***	***4***	***5***	***9***
Q2034	… in joining in community activities [for example, festivities, religious or other activities] in the same way as anyone else can? *Ku va u joyina/u ngenelela eka swihungasi /mitlango ya vaaka tiko (xikombiso, switsakiso, swa vukhongeri kumbe swin'wana) hi ndlela leyi* un'wana a nga swi kota ka ha kona?	***1***	***2***	***3***	***4***	***5***	***9***

In the last 30 days, how much difficulty did you have … *Eka masiku ya makume-nharhu lama nga hundza,u vile na ku tikeriwa ko fika kwihi*		***None*** ***Ku hava***	***Mild*** ***Kahle***	***Moderate*** ***Xikarhi***	***Severe*** ***Ngopfu***	***Extreme / cannot do*** ***Ngopfu-ngopfu/u nge koti ku endla***	***N/A***
Q2035	… concentrating on doing something for 10 minutes? *Ku va u tinyiketela ku endla xo karhi ku ringana timinete ta khume?*	***1***	***2***	***3***	***4***	***5***	***9***
Q2036	… in walking a long distance such as a kilometer? *Ku famba mpfuka wo leha wo ringana na kilomitara?*	***1***	***2***	***3***	***4***	***5***	***9***
Q2037	… in washing (bathing) your whole body? *Ku hlamba miri wa wena hinkwawo?*	***1***	***2***	***3***	***4***	***5***	***9***
Q2038	… in getting dressed? *Ku tiambarisa*	***1***	***2***	***3***	***4***	***5***	***9***
Q2039	… in your day to day work? *Eka ntirho wa wena wa siku rin'wana na rin'wana?*	***1***	***2***	***3***	***4***	***5***	***9***
Q1033	In the last 30 days, how much have you been emotionally affected by your health condition(s)? *Ka masiku ya makume-nharhu lama nga hundza,I ka ngani laha u nga kavanyeteka emoyeni hikokwalaho ka xiyimo xa wena xa rihanyu?*	***1***	***2***	***3***	***4***	***5***	***9***
Q1034	Overall, how much did these difficulties interfere with your life? *Hi ku angarela, I ka ngani laha ku tikeriwa loku ku nga nghenelela eka vutomi bya wena?*	***1***	***2***	***3***	***4***	***5***	***9***

Q2049	Besides any vision aids (eyeglasses or contact lenses) do you use any other assistive devices (cane, walker or other) for any difficulties you experience? *Handle ka swo pfuneta ku vona (tighilazi ta mahlo) kumbe swo pfuneta ku twa leswi vuriweke laha henhla,*	**1 YES** **2 NO**

In the last 30 days, how much difficulty did you have … *Eka masiku ya makume-nharhu lama nga hundza,u vile na ku tikeriwa ko fika kwihi*	***None*** ***Ku hava***	***Mild*** ***Kahle***	***Moderate*** ***Xikarhi***	***Severe*** ***Ngopfu***	***Extreme / cannot do*** ***Ngopfu-ngopfu/u nge koti ku endla***	***N/A***
u tirhisa swin'wana swo pfuneta (nhonga yo famba ha yona kumbe xin'wana) ka ku tikeriwa ku n'wana kumbe vutivi?						

Appendix 4b): Discussion guide for 69 semi-structured interviews

Section 4: Guide for in-depth interview

I am going to ask you some more general questions and I would like you to tell me all that you think about when I ask you the question. Remember there are no right or wrong answers.

A: questions for everyone

a) Reactions to questions

- I have just asked you lots of questions. How did you find these questions?
- Do you remember answering some of these questions in 2006? If yes, do you remember what you felt then?
- Has anything happened between since 2006 to make you answer differently now? If yes, what?
- Do you think these questions are about you and what is important in your life?
- Were they difficult or too sensitive? Which ones?(don't worry if can't remember which ones specifically)
- What did you think about when you answered them? (e.g. did you compare yourself to yourself at a different time or did you compare yourself to other people of the same age?)
- Any other comments on the questions

B: Questions for people who have difficulties (from early on or acquired in adulthood)

a) Time of onset of difficulty (if there is a difficulty indicated in the responses), story of the development of the difficulty and what caused it.

- How long have you had this problem?
- Tell me the story of how it happened.

b) History of treatment and ongoing support

- Tell what happened in terms of treatment you received and other support

c) Changes in self image and confidence : comparing with and without the difficulty

- Tell me about the person you were before this happened or the person you think you would be without the difficulty.
- Tell me about the person you are now.
- What are the main things that have changed or different for you because of the difficulty?

d) Changes in education and/or employment : comparing with and without the difficulty

- Were you working or studying before the onset of your difficulty and how did that change? (only for those with difficulty acquired in adulthood)
- Are you working or studying now?
- If not, would you like to be? And what is stopping you?

e) General functioning and aspects where assistance is needed

- You have told me quite a lot about what you can do and where you have difficulty. Could you tell me very briefly what is the **main** area in which you feel you have difficulty (i.e. not able to do for yourself)? And how do you feel about that?
- What is the area in which you have the least difficulty? And how do you feel about that?

- How do you cope with your difficulties?

C: Questions for everyone

a) Household structure

- Tell me who live with you and how they contribute to the household generally.

b) Important aspects of everyday life

- What things are very important to you and that you able to do for yourself?
- What is/would be the worst thing to happen to you in terms of doing activities of everyday life?
- How do you cope with the bad things?

c) Use of services

- Tell me about the services that you have in your village – e.g. health care, schools, electricity, water, toilets, shops, banks, telephone, TV, etc.
- What would you like to change about these services or are you happy with them?
- What transport do you use?

d) Time use and occupation – what person does on a typical day

- Tell me about your day yesterday. Describe for me what you did and roughly how long it took you to do each thing.
- How different is this to a typical or average day?
- Have things about your day changed recently? If yes, why?

e) Environmental barriers and facilitators : physical environment, attitudes of others

- Think about what things you have at home or other places that make it easier for you to do different activities. What are these? (e.g. adapted utensils, walking aids, other assistive devices, transport)
- What about getting to the shops or to the clinic? What makes it easier or more difficult?
- What about attitudes of other people towards you– has this been an issue for you? And have these been positive or negative? Why do you think people have these attitudes towards you?
- Do you have any difficulty with your physical environment? (By physical environment we mean buildings, pavements, roads, transport, etc.)
- Do you have difficulty with the support and attitudes of others?
- Do you have difficulty with access to information? E.g. newspapers, TV, radio, etc.

f) Income and expenditures

- Where do you and your household get most of its income – how much from selling good, wages, government grant, etc. ? (If the person or someone else in the household gets a grant, get the name of the grant and how many people get a grant)
- What are the main things that you buy with this money?
- Do you grow vegetables or keep cows, goats and chickens?
- (for those with difficulty)Tell me about the extra costs you have because of the difficulty? E.g. medicines, additional transport, paying people to assist you, etc.)
- Are you able to save any money every month or only sometimes or never?

g) Social relations and social involvement – attending community meetings, stokvel, church groups, family gatherings, having friends, etc. : comparing before and after the onset of difficulty

- Tell me about the other people in your life today – the types of relationships you have, etc. Has this changed in the last few years? If yes, why do you think these have changed?
- Do you belong to any organisation or groups (e.g. church groups, choir, stokvel, etc.) ? Has this changed in the last few years? If yes, why do you think these have changed?
- What activities happen in your village? Who takes part in these?

h) Event recall

- In the last 3 years, can you remember one of the best and one of the worst times. Please describe these.

i) Feelings about life – quality of life and satisfaction

- What makes your life happy?
- What makes your life difficult ?
- How satisfied are you with your life today?

j) Do you have any health problems? If yes would you be happy to tell me which ones and what treatment you are taking? Here are some examples:

- Deaf or hard of hearing
- Blind or low vision
- A paralysis of one or more limbs
- Amputation or loss of one or more limbs
- Head injury
- Stroke
- Asthma or other lung problems
- Diabetes
- High blood pressure or heart problems
- Epilepsy
- Tuberculosis
- Arthritis
- Psychiatric illness
- Depression
- Epilepsy
- Albinism
- Other illness or injury

k) **Are you disabled?** (yes/no/sometimes)

Appendix 5: Analysis of patterns of responses on WG Group Extended Set questions for 10 respondents

These tables present the detailed information to support the analyses in Chapter 5 for two domains – mobility and anxiety.

Summary demographics of ten respondents

Respondent number	Age	Sex	Nationality	Education level
1	55 yrs	Female	South Africa	Secondary school
2	65 yrs	Male	South Africa	Primary school
3	72 yrs	Female	South Africa	No formal education
4	53 yrs	Female	Mozambique	No formal education
5	70 yrs	Male	Mozambique	Secondary school
6	39 yrs	Female	South Africa	Secondary school
7	60 yrs	Male	Mozambique	No formal education
8	62 yrs	Male	Mozambique	Primary school
9	69 yrs	Female	Mozambique	No formal education
10	64 yrs	Male	Mozambique	Primary school

Table 5.1: Responses and explanations for 'Do you have difficulty walking or climbing stairs?' for ten respondents

Respondent Number	**Correct or incorrect interpretation**	**Explanation (I = interviewer; R = respondent)**
1 (55 yrs, F)	Correct – 'a lot of difficulty' described in her explanations but the response option seems to vary between 'some difficulty', 'a lot of difficulty' and 'cannot do'. Frustration at not being able to walk fast makes her problem a serious one. Not clear on distance references of 100m and 500m. Does house chores and ploughing while sitting down as much as possible.	D: Do you have difficulty walking or climbing steps? R: Mmm I have a lot of difficulty I: Can you describe what the difficulty is? R: I have difficulties because I exhale too much. This asthma is difficult for me and this leg as well. When I climb I can only climb 1, 2 [steps] but when I get to the third one it pains. I: Do you use equipment or getting assistance to walk? R: I don't get any assistance- I just walk. <u>About walking for 100m</u>: R: Huh! I cannot walk. I: A distance of 100 meters is equal to one side of the soccer field R: Huh, I have difficulty, what is difficulty for me is the leg I: Do you have a lot of difficulty, or some difficulty R: When I don't walk too much I have some difficulty but when I walk too much I just end up sitting down….If I walk slowly I have less difficulty but if I walk fast I have a lot of difficulty and I have to sit down. I used to walk fast but because of the leg I am unable to walk fast. I: So according to how you walk now, is it a lot of difficulty or less of difficulty? R: I feel I have a lot of difficulty because I'm not used to walking slowly. And also asthma stops me going fast, and as well as the leg stopping me immediately I try to be fast. <u>When asked if she can walk 500m</u>: R: With that I don't know because I have never do it before I:Looking at the distance you walked from the clinic yesterday to here - would you say it was a lot of difficulty or some difficulty? R: It was a lot of difficulty because I was walking a short distance and get rest. <u>When asked about climbing steps or a short hill</u>: R: I don't climb; I failed to climb that hill at Mafanyana.

2 (65 yrs; M)	Question asked incorrectly with walking and climbing asked separately. Answered correctly and seems to have a notion of distance references. Interpreted steps as a step ladder.	I: Do you have difficulty climbing steps? R: I have difficulty I: A lot of difficulty or some difficulty? R: A lot of difficulty when climbing those stairs there. I: Do you use something to help you to walk? R: I'm not helped [does not use any mobility aids] I: Do you have difficulty walking? R: Yes I have difficulty when I've been walking for along time <u>When asked about walking 100m</u>: R: On level ground 100metres I can walk it; it might be difficult for 400 metres - I can't. …I have some difficulty in walking 100m. <u>When asked about walking 500m</u>: R: Yes, it's difficult when I walk 500m. I: Is it some difficulty or a lot or you can't walk 500m? R: yes, I won't be able to walk 500m. <u>When asked about climbing steps:</u> R: yes, it can be difficult climbing steps or a hill. To climb steps, by me lifting my legs it will be difficult [referring to step ladder]….Some difficulty. [but no difficulty walking up a few steps in front of his house or around his dwelling.]
3(72 yrs: F)	Confused responses and eventually one can find some sort of response – has difficulty walking and climbing steps and uses a stick. Contradicts herself in terms of degree of difficulty. Needed much probing to get a focused response.	I: Do you have difficulty in walking or climbing stairs? I don't have difficulty, I have little difficulty, I have a lot of difficulty or you can't at all. R: Hey sir, there is a bus that stops over there, I don't use it, I'll try to get on it with the first try then the second try then the third, only will notice that I am wasting the drivers time from getting his money and driving off. [describing climbing up stairs into bus] I: Does this mean you have difficulty? R: Yes, at most times even at taxis they usually help me in. I: I asked if you have difficulties in using the stairs, do you face those difficulties. R: Yes, I face those difficulties especially getting on the bus at times if I don't have a firm grip I will usually fall on my back I: Please explain whether it means you face a lot of difficulty, a little difficulty or no difficulty R: Yes, I face a little difficulty at times [vague response in relation to later responses] I: Do you use any help to move around or walking? R: I don't usually go that far [unclear what she is referring to] I: and to walk around? R: When I go to the bottle store I walk there without any assistance but it is difficult. I: So you don't use any stick to help you? R: When i go that side I don't use anything, i rather limp to my destination but for longer distance i do use a stick because it takes long to get there. I: Do you use a stick all the time? R: I cannot walk without my stick not even to that avocado tree you see right there. It's as if I'll fall without it. [Contradicts comment above about only using stick for long distances.] I: Do you use anything else to help you to walk, besides the stick? R: There is nothing better than the stick I'm currently using - without the stick I cannot walk. I: Do you have difficulty walking on a level ground? R: Where the ground is level I can walk until where the road is. [about 200m] I: Even without the stick? Do you feel any difficulty or not? R: It only becomes difficult when I walk in places where it's not levelled; my knee gives me problems, causing me to fall. I: Do you have difficulty walking on a level ground for 500m? Equal to a soccer ground? R: I do not attend soccer matches nor walk on soccer grounds, I hardly go anywhere. I: That was just an example, what we mean is do you have difficulty walking the same

		distance? R: I don't have a problem where the ground is level, I rest every now and then - I will end up reaching my destination I: So there's no difficulty? R: Not at all <u>When asked about climbing steps or a small hill</u>: R: I won't be able to walk there. I will end up falling and hurting myself where there are stones. I don't walk up and down hills. <u>When asked about walking around her home without her stick</u>: R: I am afraid because it is very slippery inside the house at times, the stick might make me lose balance. I usually use the stick for balancing I: So would you say you have difficulties or cannot walk at all? R: Hmm, there is a lot of difficulty. <u>When asked if she can walk 100m</u>: R: I don't walk that much. Some roads have been dug up towards that side and there's a lot of grass which make it difficult for me to walk - usually fall. …. R: when I have my stick I must always walk on level ground, where there's a little wall, that's when i have difficulty. Even where it's down hill, it's difficult because it's as if I might fall. I: even with your stick? R: yes , even with the stick. …. I: how much difficulty do you have even with your stick? R: I have a lot of difficulty especially on unlevelled fields or ground.
4 (53yrs; F)	Correct – 'no difficulty' with initial confusion on what type of steps; does not use any mobility aid	I: Do you have difficulty walking or climbing steps R: step ladder? I: No, it's not steps on a step ladder, it's steps like in the reservoir there. R: Climb them? I: Do you have difficulty climbing those steps? R: I don't have difficulty. I climb the stairs and walk. <u>When asked about walking 100m</u>: R: I walk by myself I: Do you understand what a distance of 100 meters is R: yes, I can walk to Croquet Lawn. [more than 10 kms]. <u>When asked about climbing steps or a small hill</u>: R: I climb a small hill and walk.
5 (70yrs; M)	Correct – has difficulty intermittently because of asthma; has reasonable understanding of distances; not consistent problem because of asthma. Does not use any mobility aid.	I: Do you have difficulty walking or climbing steps R: No I: Not at all R: Walking, I don't have difficulty I walk well I: Climbing stairs? R: I have a problem then because I also have asthma <u>When asked about walking 100m</u>: R: I don't get difficulty at times, it's only sometimes. Sometimes I have difficulties and sometimes I don't have difficulties. So I don't know how to put it. <u>When asked about walking 500m</u>: R: A level place, I walk well <u>When asked about climbing steps or small hill</u>: R: Climbing, I'm holding on the sides. [i.e. has difficulty] I: Do you have a lot of difficulty or some difficulty? R: Some difficulty <u>When asked about walking round his home</u>: R: Lot of difficulty

		I: Explain what you understand as home or show what 'at home' is. R: At home - I mean where my yard end …. I: Now why do you have a lot of difficulty walking around your yard but you have some difficulty sometimes walking 500 meters? Can you tell me the difference? R: Thing is 100metres and 500 meters are the same I: Okay, between that and walking around your home R: It depends – sometimes I don't feel so bad but sometimes I can't walk to the road. I: So um' can you describe to me when you can't walk. What is going on? R: I feel short of breath [from asthma]. I: Okay, …what makes it difficult in your home to walk around? R: I don't measure it, I can go around it, and my stand is big from there to there to there. [i.e. stand looks like it may be bigger than 500m]. <u>Explaining reason for difficulty walking</u>: R: My difficulty is me not being able to breathing. It's not my legs, my legs are alright but its breathing which makes me not able to walk. ….If I start not breathing properly I have to stop walking. …I have difficulty breathing, not walking.
6 (39 yrs; F)	Correct – 'no difficulty'. Walks long distances and does not have any difficulty.	I: Do you have difficulty walking or climbing steps? R: No I: Is it no difficulty for walking and climbing steps? R: I do climb steps in Hazyview [nearest town], I have no difficulty <u>When asked about walking 100m</u>: R: I have no difficulty; if you can see where I fetch wood - you can see that I can walk. [points to an area of more than 500m away] I: Is it more than 500 meters? R: Huh, it's too far. Can you see those trees over there? It's too far.
7(60yrs; M)	Struggles to use response options and provide a single response; provides long description of issue; has 'no difficulty' in relation to question intent. Age related changes in ability to walk. Does not use any mobility aid.	I: Do you have difficulties walking or climbing a stair / steps? R: Climbing a Stairs? [Asks whether it is a step ladder.] I: Let's ask again. Do you have difficulty walking or climbing steps? We don't mean a step ladder, we mean such as steps entering the room or walking in the place… R: Going upwards? I: Yes R: Er…because I'm now old it's no longer as the time I was going like walking from home [Mozambique] to here. It's no longer the same as when I was still younger because my knees were still strong. I: Does this mean you have some difficulty walking and climbing steps because you are old, or does it mean you don't have difficulty? R: I can walk but I cannot walk like before. Previously I use to run but now I cannot run from here to there because I'm old, but the time I was still a boy I used to run for a distance. I: Does this mean you have some difficult or no difficulty? R: Yes because it depends on the age because we cannot run the same. [not giving a clear response, but suggesting 'some difficulty'] I: The way you are explaining, does it mean that you have difficulty walking compared to the time you were young, as well as climbing the steps? Do you have difficulties? Actually we want to know if you have difficulty, some difficulty or no difficulty walking and climbing steps at the moment? R: But I can walk for long distance but when I come back I just feel tired. [suggesting 'no difficulty']. <u>When asked about walking 100m</u>: R: I have no difficulty. I don't get tired. …If maybe it's a long distance, such as walking from here to Aereagh [village about 15 kms away] and come back home, then I feel tired. <u>When asked about walking 500m using a soccer field as an example</u>:

		R: A soccer field is too small. It doesn't mean a thing to me. When asked about climbing steps or a small hill: R: I climb the steps but it won't be the same as before but I can also climb the hill.
8(62yrs; M)	Correct – responses of 'no difficulty' are congruent with examples and explanations; does not use any mobility aid; while he is able to walk far he is comparing his ability to what is was before.	I: Do you have difficulty walking or climbing steps? R: I have no difficulty walking I can walk. I don't know with steps because I have not yet climbed steps because I don't go to places where there are steps. When asked about walking 100m: R: I have no difficulty walking. I've not yet experienced any difficulty walking. When asked about walking 500m: R: I have no difficulty walking except running. ….. R: I can walk but it's just that nowadays I cannot walk a long distance. But I can walk from Agincourt to here. [about 20 kms]….without feeling tired. When asked about climbing steps or a small hill: R: I have no difficulty
9(69yrs; F)	Correct – 'no difficulty' responses concur with examples and explanations; she does not use any mobility aids.	I: So do you have difficulties walking or climbing steps? R: I have no difficulty. When asked about walking 100m: R: I have no difficulty. When asked about walking 500m: R: I have no difficulty. When asked about climbing steps or a small hill: R: I can climb.
10 (64 yrs;M)	Correct – 'no difficulty' responses concur with descriptions given. He does not use any mobility aids.	I: Do you have difficulty walking or climbing steps? When we say steps we mean steps like the one in town that you climb to [get to] the next building. R: I have no difficulty I: Are you thinking about walking and climbing when you say you don't have difficulty? R: Yes When asked about walking 100m: R: I have no difficulty I: Do you understand the distance of 100 meters? R: Yes I do understand. 100 meters is like that way that goes down there - it's 100 meters. [Shows a distance of approximately 100m]. When asked about walking 500m: R: I have no difficulty walking half akilometre. [Spontaneously used 'half km' reference]] I: How far can you walk? R: I walk 8 to 10 kilometres When asked about climbing steps or a small hill: R: No difficulty

Table 5.2: Responses and explanations for 'How often do you feel worried, nervous or anxious? Is it daily, weekly, monthly or few times in a year or never?' for ten respondents

Respondent Number	Correct or incorrect interpretation	Explanation I = interviewer; R = respondent
1 (55 yrs, F)	Unable to conclude on correctness of interpretation.- no elaboration	I: How often do you feel worried, nervous or anxious? Is it daily, weekly, monthly or few times in a year or never? R: Never
2 (65 yrs; M)	Correct – 'never' response concurs with his explanation.	I: How many times did you feel worried, scared or anxious? Is it everyday, weekly, monthly or a few times in the year or never? R: There isn't - never. I: What can make other people worry?

		R: Things which make other people worry is that their family affairs are not well. They worry a lot that they don't have food and other things. That's the reason that will make them worry.
3(72 yrs: F)	Seems to be correct in her interpretation but she gets sidetracked and she struggles to use the response options.	I: How often are you worried, nervous or anxious - has it happened daily, weekly, monthly or a few times a year or it never happens? R: That happens a lot, because of the thieves, you'll hear that they broke into someone's house and stole. So your heart always pains. I: does it happen everyday, weekly, monthly or a few times a year? R: if I worry this week, the following week I don't worry anymore but in the following week I hear of a breaking, my heart starts paining again. I: Have you ever been attacked by thugs R: They always break in here – when I'm asleep. I: Does it happen often? R: No, it happens usually when they know that I came from the field. They know that I don't have a child here. So it's better they come steal. I: So when you worry, do you take medication to stop you from worrying or things like that? R: No I don't take any <u>When asked about the level of anxiety the last time she felt anxious</u>: R: My heart was just very painful. [does not use response options] I: was it very painful or too much? R: Yes, I would see unbelievable things, and thought maybe I was getting a heart attack, but no…. I: Think of the last time you felt worried, would you say it was unusual or better than the usual or it was same as usual? R: When the pain comes, it would really make my heart beat fast. I would finish a bottle of water, thinking that maybe it would stop, and it wouldn't. I: Was it more than usual? R: Yes, it beats fast. …. R: it often stops and when it does, my heart isn't sore, even in my head I feel fine.
4 (53yrs; F)	Correct – her 'few times a year' response is substantiated a few times by her claim that her only problem is her sicknesses - diabetes and hypertension. Her responses (e.g. about taking medication) are focused on these two illnesses rather than anxiety.	I: How often do you feel worried, nervous or anxious, does it happen everyday, or weekly, monthly or, few times in a year, or it has never happen? R: It only happened that time. I: Does it happen daily, weekly, monthly, few times a year or it never happens? R: It might happen once a year. I: Can you explain when it happens? R: It doesn't happen every time but sicknesses come up sometimes. I: Do you take medication for your anxiety? R: I use pills I: Are the tablets for anxiety? R: No, I use them for diabetes and high blood. I: Think about the last time you had anxiety - was it mild, moderate or severe? R: I don't have anxiety that's painful; the pain is when its high blood and thing are not going well it hurts. I: Can you say that's worry or fear that you are feeling? R: Once they tell you that you have this, when you feel it you will no longer be scared. I: Think about the last you felt anxious was your anxiety more than usual, was it better than usual or was it almost the same as usual? R: No
5 (70yrs; M)	Correct – anxiety as 'normal things' and occurring a few times a year. Ongoing rather than episodic nature of	I: How often do you feel worried or nervous or anxious? Its everyday, weekly, monthly or a few times in a year or is it never. R: Worried in what way? I: Any way in which you were worried, nervous or anxious how many times has it

	anxiety. Inability to measure therefore unable to use response options.	happened? R: A lot of times. I: Is it everyday, weekly, monthly or few times in the year? R: A few times [in the year]… As normal things. I: Can you give an example if you remember getting very anxious or worried? R: It's circumstances in life which sometimes go to a point which scare me. I used to think that the things I'm seeing are not good. Seeing a lot of things makes me worried or anxious. I: Do you take anxiety medication? R: No I: Remember the last time you had anxiety can you say it was mild, moderate or severe? R: I still have it. I: Is it severe or moderate? R: I can't measure it. I: Think of the last time you had anxiety, was it normal, or better than normal or was it almost the same as normal. R: There's no change in me, when it comes to thinking about things in the world and life. I can say it's still the same. …. R: …We are born with anxiety. Even children have it.
6 (39yrs; F)	Correct – points out that just nervous and scared. External element causing nervousness.	I: How often do you feel worried, nervous or anxiety, does it happen daily, weekly, monthly, few times in a year or never happen? R: Huh, I'm just nervous, I'm scared of something that move on top of the house during the night. I: How many times? R: Many times; it scares us; even yesterday we didn't sleep. I: Does it happen weekly, monthly, daily…? R: It happens weekly. I: Does it come during the night? R: Yes. We are scared of it. I: Do you know what is it? R: I don't know. You will not know something during the night. I: Do you take medicine for anxiety? R: No I: Think about the last time you were anxious; would you say it was mild, moderate or worse? R: No it wasn't worse but we just hid inside during that time. I: Was it moderate, mild… R: It was moderate. I: Thinking about the last time you were anxious, was your anxiety worse than usual, better than usual or close to usual? R: I don't know
7(60yrs; M)	Correct – anxiety as normal part of life – linked to thinking and having wishes in life. Not giving clear responses.	I: How often do you feel worried, nervous or anxious? Is it daily, weekly, monthly or few times in a year or never get worried, nervous or anxious? R: When you say worried, you mean losing or something? I: Just being worried. R: Everybody has to worry because when I'm always thinking I am worried. And when I just sit at home, I get worried because I don't get what I want. And as I mentioned that my children are not employed, that's worries me. I'm worried when my children don't get what they've worked for. I: So, how do you worry, daily, weekly or few times in a year? R: I get worried once and take time to get worried. I: Is your worry due to the normal life or is because of not having money? R: My worry is due to normal life.

		I: Is it because of life? R: Yes, because a normal person will get worried sometimes because if you don't get worried it means that you don't have wishes. If you are normal you have to worry sometimes.
8(62yrs; M)	Correct – anxiety is seen as arising from unmet needs.	I: How often did you feel worried, nervous or anxious - is it daily, weekly, monthly, or few times in a year or never? R: Never I: What makes people get worried? R: Because of not getting a useful things that are important to them. I: Do you get enough things? R: It's not enough but deep inside my heart I tell myself that what I have is enough for me. I: Do you take medication for anxiety? R: No.
9(69yrs; F)	Seems to be correct although information on interpretation is limited.	I: How often do you feel worried, nervous or anxious - do you feel it daily, weekly, monthly, few times in a year or never? R: I didn't feel nervous or anxious. I: Didn't you feel worried, nervous or anxious? R: No.
10 (64yrs;M)	Seems to be correct although information on interpretation is limited.	I: How often do you feel worried, nervous or anxious - do you feel it daily, weekly, monthly, few times in a year or never? R: Never worried.

Appendix 6a): Coding of life factors for profile analysis

- Disability status: 1 = yes, disabled; 2 = no, not disabled
- Health condition (HC): 1 = yes(i.e. a HC was reported at some point in the interview); 2 = no HC (i.e. no HC was mentioned)
- Receipt of a grant: 1 = yes received in household (could be any number in the household); 2 = no grant in household. Note was made of the type of grant(s) received.
- Salary or income other than a grant: 1 = yes; 2 = no; 3 = don't know or not specified
- Life satisfaction: 1 = yes satisfied; 2 = no not satisfied; 3 = don't know/non committal
- Main reason given for satisfaction: 1 = health related; 2 = non-health related; 3 = family/other; 4 = combination of 1, 2 and/or 3.
- Statement of religious belief (at some point in the interview): 1 = clearly stated that he or she is Christian or believer in God; 2 = no mention made of religion.
- Household structure: 1 = lives alone; 2 = lives with one other person; 3 = lives with 2 or more other people.
- Age: 1 = 18 – 39 years; 2 = 40 – 59 years; 3 = 60 – 79 years; 4 = 80+ years
- Level of activity: (lower score means less activity outside of the household – activity being defined as household, social activities or other activities); codes 1 and 2 were applied predominantly for respondent without gainful activities or employment, while codes 3 and 4 were applied predominantly for people who do have employment or some gainful activity.
  - 1 = all activity is within the house/dwelling area (cleaning, sweeping yard, cooking, etc.), gardening and fetching water
  - 2 = ploughing of field, herding cattle in addition to household activities
  - 3 = casual or piece work for money (e.g. sewing traditional mats; making traditional beer; selling sweets)
  - 4 = regular employment either at home (sewing clothes) or going out to work on a daily basis.
- Assets: Lower scores reflect less assets, such as having chickens, goats and cows. The possession of one or more goats or cows usually means a household also possesses chickens, as was noted in the observations during data collection.
  - 1 = no chickens. May grow vegetables for household use.
  - 2 = only has chickens
  - 3 = has one or more goats
  - 4 = has one or more cows
- Savings: the household's ability to save any money at the end of the month: 1 = yes; 2 = no; 3 = not specified
- Social networks: based on who they said was important for them and who they mentioned in the interview as being someone they visit or consult when experiencing problems:
  - 1 = only family
  - 2 = family + neighbours
  - 3 = family + neighbours + friends not necessarily living close by.
  - 4 = no one

- Organisational involvement:
  - 1 = none
  - 2 = church/stokvel[59]/burial society (*tswelapelo*). These are very common.
  - 3 = broader community activities such as being on the local school governing body.

Appendix 6b): Scaling of response profiles to determine severity and type of profiles

In the tablebelow, I set out the domain categories together with the multiplier factor, described in chapter 3, and applied to each score. The WG and SAGE questions are included.

For the data captured, a total domain score was computed as follows:

- The responses for the relevant questions were summed to give the total
- The total was multiplied by the relevant multiplier
- The resulting score was the total domain score
- The seven total domain scores were summed to provide a total functioning score between 0 and 140, where a low score indicates good reported functioning and a high score poor reported functioning. At this stage, no decision was made as to the different possible cutoff points between 'disabled' and 'non-disabled'. This decision is made below in the severity categorisation.
- The total functioning score (TFS) was categorised as follows and each respondent's score coded correspondingly for ease of analysis:
    - 0-39
    - 40-49
    - 50-59
    - 60-69
    - 70-79
    - 80-89
    - 90-99
    - 100-109
    - 110-119
    - 120-140

[59] A stokvel is an informal savings group, where members meet regularly and each contributes towards a common pool of money. Each member has a turn to use the pool of money.

Table A6: Combination of domain questions for domain average scores

Domain	WG question (6 domains)	SAGE question (7 domains)	Total score for questions (SAGE only) = number of questions X 5 response options	Multiplier factor for scaled score(SAGE only) Total contribution of each domain = 20/140
Sensory	• Seeing even when wearing glasses • Hearing even when using a hearing aid	• Seeing far • Seeing near	2X5 =10	Each score to be multiplied by 20/10 = 2
Mobility	• Walking and climbing steps	• Moving around • Standing for long • Walking long distance	3X5 = 15	Each score to be multiplied by 20/15 = 1.333
Cognition	• Remembering • concentrating	• remembering and concentrating • learning a new task • concentrating for 10 minutes	3X5 = 15	Each score to be multiplied by 20/15 = 1.333
Communication	• understanding and being understood in usual language	• NO QUESTIONS	N/A	N/A
Self-care	• Self-care – washing all over and dressing	• Self-care (bathing and dressing) • Dressing • Washing whole body	3X5 = 15	Each score to be multiplied by 20/15 = 1.333
Affect (anxiety and depression)	NO QUESTIONS	• Problems with worry and anxiety • Problems with feeling sad, low, depressed	2X5 = 10	Each score to be multiplied by 20/10 = 2
Sleep	NO QUESTIONS	• Problem with sleeping	1X5 = 5	Each score to be multiplied by 20/5 = 4
Pain	NO QUESTIONS	• Bodily aches or pains	1X5 = 5	Each score to be multiplied by 20/5 = 4

Appendix 7: Summary description of 69 respondents' functioning and life context profiles

Respondent number	Village code	Sex	Age	Functioning profile Type (Main domain)	Functioning Profile severity**	Life satisfaction (Yes=1, No=2 DK/non-committal=3)	Disability status (1=disabled 2 =Not disabled)	Health condition (1=Yes 2=No)	Income (1 = lowest, 2, 3, 4 = highest)	Social support (1 = low 2 = moderate 3 = good)	Religious (1 = yes 2 = no)
1	8	F	2	Cognition	moderate - 3	1	2	1	2	1	2
2	8	F	2	Affect	mild - 2	1	1	-	2	2	2
3	8	F	2	None	no – 1	1	2	2	2	2	2
4	8	M	3	Sleep	mild - 2	1	2	1	3	2	2
5	8	F	4	Pain	moderate - 3	2	2	1	2	2	2
6	8	M	2	Sleep/affect	mild - 2	1	1	1	1	1	1
7	8	M	3	Pain /sleep	mild - 2	1	2	1	1	2	2
8	8	M	4	None	no – 1	1	2	2	2	2	2
9	8	F	1	None	no – 1	2	2	2	2	2	2
10	8	M	1	Pain/affect	mild - 2	1	2	1	4	2	1
11	8	F	1	None	no – 1	1	2	2	4	2	2
12	10	F	3	Affect	moderate - 3	1	1	1	3	2	1
13	10	F	2	None	no – 1	1	2	1	4	3	1

Respondent number	Village code	Sex	Age	Functioning profile Type (Main domain)	Functioning Profile severity**	Life satisfaction (Yes=1, No=2 DK/non-committal=3)	Disability status (1=disabled 2 =Not disabled)	Health condition (1=Yes 2=No)	Income (1 = lowest, 2, 3, 4 = highest)	Social support (1 = low 2 = moderate 3 = good)	Religious (1 = yes 2 = no)
14	10	F	3	Sleep	mild - 2	1	2	1	2	1	2
15	10	F	2	Sleep	moderate - 3	1	2	1	4	3	2
16	10	M	3	Pain	mild	1	2	1	3	2	1
17	10	F	3	Sleep	mild	1	2	1	3	1	2
18	10	M	2	None	no – 1	1	2	1	4	3	1
19	10	F	2	Cognition	mild - 2	3	2	1	2	2	2
20	10	F	3	Pain	severe - 4	1	1	1	2	2	2
21	10	F	1	Cognition	extreme - 5	3	1	1	2	2	2
22	10	M	3	Affect/Pain	severe - 4	?	1	1	1	1	2
23	10	F	2	Affect	moderate	1	2	1	1	2	1
24	10	M	4	Sensory	moderate - 3	3	1	1	3	2	2
25	10	F	3	Pain	moderate - 3	3	2	1	2	2	1
26	10	F	3	Sleep	mild - 2	3	2	1	2	2	1
27	11	F	1	Pain/ affect	mild - 2	1	2	1	3	2	1
28	11	F	3	None	no – 1	1	2	2	3	2	2
29	11	M	3	Pain	severe - 4	1	2	1	4	2	2

Respondent number	Village code	Sex	Age	Functioning profile Type (Main domain)	Functioning Profile severity**	Life satisfaction (Yes=1, No=2 DK/non-committal=3)	Disability status (1=disabled 2 =Not disabled)	Health condition (1=Yes 2=No)	Income (1 = lowest, 2, 3, 4 = highest)	Social support (1 = low 2 = moderate 3 = good)	Religious (1 = yes 2 = no)
30	11	F	3	None	no – 1	1	2	2	2	2	1
31	11	M	2	None	no – 1	1	2	1	2	2	1
32	11	M	3	Pain/sleep	mild - 2	1	2	1	3	2	2
33	11	M	3	None	no – 1	1	2	1	2	2	2
34	11	F	3	None	no – 1	1	2	2	2	2	1
35	11	F	3	Mobility	moderate - 3	1	2	1	?	?	1
36	11	F	2	Pain/ sensory	moderate - 3	1	1	1	2	2	2
37	11	F	2	Mobility	extreme - 5	3	2	1	3	2	1
38	11	F	3	Affect	mild - 2	1	2	2	1	2	2
39	11	F	2	None	no - 1	1	2	2	3	2	2
40	11	F	2	Sleep	mild - 2	1	2	1	4	2	2
41	11	M	3	Affect	moderate - 3	3	2	1	3	1	1
42	11	F	3	Sleep	mild - 2	1	2	1	2	2	1
43	11	M	3	Pain/sensory/ mobility	extreme - 5	3	2	1	1	2	2
44	16	M	3	Sleep	moderate - 3	1	2	1	2	2	1
45	16	F	3	Sleep	moderate - 3	1	1	1	1	1	1

Respondent number	Village code	Sex	Age	Functioning profile Type (Main domain)	Functioning Profile severity**	Life satisfaction (Yes=1, No=2 DK/non-committal=3)	Disability status (1=disabled 2 =Not disabled)	Health condition (1=Yes 2=No)	Income (1 = lowest, 2, 3, 4 = highest)	Social support (1 = low 2 = moderate 3 = good)	Religious (1 = yes 2 = no)
46	16	F	2	Pain	moderate - 3	1	2	1	3	2	2
47	16	F	2	Pain/sleep/ affect	severe - 4	1	2	1	3	2	2
48	16	M	3	Sleep/affect	moderate - 3	2	2	1	3	2	2
49	16	M	3	Sleep	moderate - 3	2	2	1	3	2	2
50	16	M	3	Sleep	severe - 4	2	1	1	1	2	2
51	16	F	2	Pain	moderate - 3				?	?	?
52	16	F	1	None	no - 1	1	2	2	3	2	2
53	16	F	4	Affect	moderate - 3	3	2	1	2	2	2
54	16	F	2	Sensory	mild - 2	1	2	1	1	2	2
55	16	M	4	Sensory	severe - 4	3	1	1	3	2	2
56	16	F	1	None	no - 1	2	2	2	3	2	2
57	16	F	4	Pain/sleep	severe	3	2	1	2	1	2
58	20	F	3	Pain	mild - 2	1	2	1	2	2	1
59	20	F	2	None	no - 1	1	1	2	2	2	1
60	20	M	2	None	no - 1	2	2	1	2	3	2
61	20	M	2	None	no - 1	1	2	2	3	2	1

Respondent number	Village code	Sex	Age	Functioning profile Type (Main domain)	Functioning Profile severity**	Life satisfaction (Yes=1, No=2 DK/non-committal=3)	Disability status (1=disabled 2 =Not disabled)	Health condition (1=Yes 2=No)	Income (1 = lowest, 2, 3, 4 = highest)	Social support (1 = low 2 = moderate 3 = good)	Religious (1 = yes 2 = no)
62	20	F	4	Pain	None as score but many missing responses	2	1	1	?	?	1
63	20	F	3	Sleep	severe - 4	1	1	1	1	1	2
64	20	M	3	None	no - 1	1	2	1	3	3	2
65	20	F	2	Sleep/pain/ affect	severe - 4	2	2	1	1	2	2
66	20	F	1	None	no - 1	3	2	1	4	2	1
67	20	M	3	None	no - 1	1	2	2	3	2	2
68	20	F	3	None	no - 1	1	2	1	3	2	2
69	20	F	3	Pain/mobility/ cognition	moderate - 3	3	2	1	3	2	1

**severity rating - TFS

- no difficulty: 0-39
- mild difficulty: 40-59
- moderate difficulty: 60-79
- severe difficulty: 80-99
- extreme difficulty: 100+

Appendix 8: Ethics Clearance certificates

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Schneider

CLEARANCE CERTIFICATE	**PROTOCOL NUMBER M080222**
PROJECT	Factors determining people's responses to self-report questions on functioning and disability
INVESTIGATORS	Ms M Schneider
DEPARTMENT	School of Public Health
DATE CONSIDERED	08.02.29
DECISION OF THE COMMITTEE*	Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 08.03.25 **CHAIRPERSON** .....
(Professor P E Cleaton Jones)

*Guidelines for written 'informed consent' attached where applicable

cc: Supervisor : Dr J Goudge

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

(M. SCHNEIDER) 11/4/2008

Ethics clearance was obtained for the 21 StatsSA focus group study in early 2006. The reference number is R14/49 for Protocol M060125: Development and Testings of a Disability Question Schedule for census 2011. The certificate has been lost due to changes in my employment. A replacement has been requested.