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Disability Measurement and Uptake of Sexual and Reproductive Health Services in Malawi

By

Monica Zione Jamali

<u>Thesis for the degree of Doctor of Philosophy</u>

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Abstract

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Addressing the sexual and reproductive health needs of persons with disabilities has been one of the development challenges confronting the global community since the 1994 International Conference on Population and Development (ICPD). This challenge has been more critical in sub-Saharan Africa due to limited availability of disability data, poor-socio-economic status of persons with disabilities and the lack of a universally agreed upon conceptual understanding of disability. Researchers have attempted to address data limitation problems by developing impairment and functional screens that have been used to estimate the proportion of persons with disabilities. However, little has been done in the sub-Saharan African region to examine the various approaches used to measure disability and their relationship with the uptake of sexual and reproductive health services among persons with disabilities.

Using anchoring vignettes techniques and Compound Hierarchical Ordered Probit Modelling, this study has examined the self-reported measurement of disability in Malawi. The study has also examined the relationship between impairment and functional limitation as measures of disability with uptake of sexual and reproductive health services using logistic regression models. Among the sexual and reproductive health services used in the analysis are use of modern contraceptive methods, HIV counselling services, place of delivery and professional assistance during childbirth.

Controlling for demographic variables such as age and place of resident, this study has found that there are significant variations in use of HIV counselling services by severity of functional disabilities, where women with severe functional disabilities are less likely to use HIV counselling services compared to those with no functional disabilities. This study has also found that there are measurement problems related to the self-reported disabilities. For instance, the study has found that survey respondents use their health expectations and conceptual understanding of disability to respond to questions on functional disabilities. The use of individual understanding of disabilities is likely to affect the accuracy of disability estimates since there is no standardised definition of disability in the country. The low use of HIV counselling service among women with severe functional disabilities implies that most women with functional disabilities are not aware of their HIV status. This necessitates the need for intensifying the provision of HIV counselling information to women with functional disabilities.

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Acknowledgements

Definitions and Abbreviations

ADL	Activities of Daily Living
BLM	Banja La Mtsogolo
CBM	Christian Blind Mission
CHOPIT	Compound Hierarchical Ordered Probit model
CRPD	Convention on the Rights of Persons with Disabilities
DALYS	Disability Adjusted Life Years
DEWODE	Disabled Women in Development
DHS	Demographic and Health Survey
FPAM	Family Planning Association of Malawi
GIS	Geographic Information System
GPS	Global Positioning System
HRBA	Human Rights Based Approach
ICF	International Classification of Functioning, Disability and Health
ICIDH	International Classification of Impairment, Disabilities and Handicaps
ICPD	International Conference on Population and Development
MACOHA	Malawi Council for the Handicapped
MDHS	Malawi Demographic and Health Survey
MICS	Multiple Indicators Cluster Surveys
MWHS	Malawi World Health Survey
PHC	Population and Housing Census
QALY	Quality Adjusted Life Years
SDG	Sustainable Development Goals
SDI	Sampling Deviation Index
SF-36	36 Item Short Form Health Survey
SRH	Sexual and Reproductive Health
UN	United Nations
UNFPA	United Nations Population Fund
UNICEF	United Nations International Children's Emergency Fund
U.K	United Kingdom
U.S.A	United States of America
WHO	World Health Organization
WHODAS 2.0	World Health Organization Disability Assessment Schedule
WHS	World Health Survey
YLD	Years Lived with Disability

1 Chapter 1: Introduction

1.1 Background

The sexual and reproductive health (SRH) of persons with disabilities has been an area of interest to population researchers ever since the adoption of the 1994 International Conference on Population and Development (ICPD) Programme of Action which recognised persons with disabilities as a significant part of the World's population (UNFPA, 2014). Persons with disabilities as described by the United Nation Convention on the Rights of Persons with Disabilities (CRPD), are "those who have long-term physical, mental, intellectual or sensory impairment which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others", (Hendricks, 2007). To ensure that persons with disabilities access SRH services, the ICPD Program of Action requests member states to create awareness about disability issues and urges governments to improve access to information, education and SRH services, including family planning and HIV and AIDS, among persons with disabilities (Kwadwo, Anafi and Sekyere, 2014; UNFPA, 2014). The ICPD Program of Action also urges all member states to eradicate all forms of discrimination encountered by persons with disabilities when they are exercising their SRH rights.

The SRH of persons with disabilities has also attracted global attention following the development of the United Nations Convention on the Rights of Persons with Disabilities, particularly Article 25 which advocates for non-discrimination in healthcare provision and affordable healthcare services (Hendricks, 2007; Kwadwo, Anafi and Sekyere, 2014). The CRPD advocates for the provision of the highest possible standards of health (including sexual and reproductive health) to persons with disabilities, at a cost that is affordable and within the same range, quality and standards as that of persons with no disabilities (Hendricks, 2007). The attention of the global community has also been drawn towards the SRH needs of persons with disabilities after the inclusion of disability issues in the United Nations Standard *Rules on the Equalization of Opportunities for Persons with Disabilities (United Nations, 1994) and Sustainable Development Goals* (SDGs) (United Nations, 2015a) .

Apart from the Global community, persons with disabilities and disability activists in developed countries like the United State of America (U.S.A) and the United Kingdom (U.K) have also recognised the importance of accessing SRH services (Nosek *et al.*, 1995; Shakespeare, 2000; Ganle *et al.*, 2016). In the U.K, persons with disabilities have recognized that disability rights movements have concentrated on advocating for the right to employment, education and

housing but not on their SRH as articulated in the following British feminist with a disability, Liz Crow's statement;

> "I've always assumed that the most urgent Disability civil rights campaigns are the ones we're currently fighting for- employment, education, housing transport etc., etc., and that next to them a subject such as sexuality is almost dispensable. For the first time now I'm beginning to believe that sexuality, the one area above all others to have been ignored, is at the absolute core of what we're working for. […] It's not that one area can ever be achieved alone-they're all interwoven, but you can't get closer to the essence of self or more 'people living-alongside-people' than sexuality, can you?"(cited in Shakespeare, 2000 ,p.165)

In the U.S.A, Nosek et al (1995) observed that women with physical disabilities needed SRH services but they were experiencing attitudinal and architectural barriers when accessing the services as demonstrated in the following excerpt;

> "Could you believe that all through my pregnancy so far, they don't know how much weight I've gained, because they don't have a wheelchair or sitting scale. They don't monitor my weight at all. I know in pregnancy that's important. You need to know. I've gone to different doctors where the tables are so high that it's almost impossible to jump up there", (Nosek *et al.*, 1995).

The above two excerpts illustrate the need and experience of persons with disabilities when accessing SRH services.

With regards to sub-Saharan Africa, interest in the SRH of persons with disabilities has grown because of the increase in reports of experiences of sexual violence and abuse among persons with disabilities (Smith *et al.*, 2004; Wazakili, Mpofu and Devlieger, 2006; Stöpler, 2007; Rusinga, 2012; Van Rooy and Mufune, 2014). For example, in Kenya, about 15% to 20% of girls with disabilities are estimated to experience physical and sexual violence (Stöpler, 2007). In Zimbabwe, 9.2% of women with disabilities experience physical and sexual abuse compared to women with no disabilities (whose proportional experience is 5.6%) (Zimbabwe Ministry of Health, 2013). De Beaudrap et al (2014) also reports that between 2000 and 2013, HIV prevalence among persons with disabilities in sub-Saharan Africa has increased from 1.1% to 29%. The growing number of persons with disabilities due to humanitarian warfare and natural disasters in sub-Saharan Africa has also made it impossible to ignore the SRH needs of persons with disabilities in the region (Barriga and Kwon, 2010; Moyo, 2010; De Beaudrap, Mac-Seing and Pasquier, 2014; ACFA, 2017).

Despite the global community's initiative, persons with disability advocacy and the region's interest in the SRH of persons with disabilities, persons with disabilities in the sub-Saharan Africa region continue to face challenges when accessing SRH services (Smith *et al.*, 2004; WHO and UNFPA, 2009; Ahumuza *et al.*, 2014). Reported challenges include non-accessible infrastructures (Ahumuza *et al.*, 2014; Tanabe *et al.*, 2015), lack of SRH education (Kassa *et al.*, 2016) and limited contraceptive options specifically for persons with disabilities (Nosek *et al.*, 1995; Becker, Stuifbergen and Tinkle, 1997). Persons with disabilities also experience discrimination and stigma (Smith *et al.*, 2004), service provider's negative attitude (Tanabe *et al.*, 2015), poverty (Smith *et al.*, 2004; Ahumuza *et al.*, 2014); exclusion of disability issues in SRH policies and programs (Kwadwo, Anafi and Sekyere, 2014) and lack of disability data (De Beaudrap *et al.*, 2016).

Efforts by social and health science researchers to address the SRH needs of persons with disabilities in the region have included; an assessment of the SRH of persons with disabilities and the challenges faced when accessing SRH services (Smith *et al.*, 2004; Ahumuza *et al.*, 2014; Mavuso and Maharaj, 2015; ACFA, 2017). The development of disability measurement tools like the Washington Group short set of questions (Mont, 2007a; Loeb, Eide and Mont, 2008; De Beaudrap *et al.*, 2016), and an examination of SRH policies to understand how disability issues are being addressed (Kwadwo, Anafi and Sekyere, 2014). Little has been done to understand the issues surrounding the measurement of disability and its implications on access to SRH services. Yet it is measurement outcomes that provide estimates of persons with disabilities in need of health services and guides in the development of policies and programmes on disability inclusive SRH services (Smith *et al.*, 2004; Mont, 2007a; Palmer and Harley, 2012). Moreover, it is not sufficient to address the SRH needs of persons with disabilities without understanding the scope of disability, that is understanding the severity of disability or how particular health conditions in interaction with environmental barriers and facilitators affect people in their everyday lives (WHO and World Bank Group, 2011).

Concerning Malawi, few studies have targeted persons with disabilities with an aim of providing SRH services, yet their uptake of SRH services is low compared to persons without disabilities (World Health Organization, 2003; Munthali, Mvula and Ali, 2004). For example, only 28% of persons with disabilities have ever used any family planning methods compared to 51% of persons without disabilities (Munthali, Mvula and Ali, 2004; NSO, 2005). Policies and programmes on health service delivery in the country including the *National Sexual and Reproductive Health and Rights (SRHR) policy* are also developed based on disability data that is collected through use of disability measures that produces low estimates of persons with disabilities (Ministry of Health, 2012; Malawi Government, 2015;2016; Ministry of Health, 2017). Such measures include impairment measures, which ask the household participants if a household member has a

disability (NSO, 2008; WHO and World Bank Group, 2011). According to the 2010 WHO and World Bank disability report, impairment measures provide low estimates of persons with disabilities because they do not collect data on persons with chronic health conditions, communication difficulties and other minor impairments (WHO and World Bank Group, 2011). Impairment measures are also not a good source of disability data because they do not provide sufficient estimates of persons with disabilities due to their focus on severe cases of disabilities (Palmer and Harley, 2012). The under-estimation of persons with disabilities means that the SRH needs of persons with chronic health conditions such as depression and cognition are not being addressed because they are not recognized as persons with disabilities. The under-estimation of persons with disabilities also presents a missed opportunity in mitigating the spread of HIV and AIDS, since there are high levels of coercive or unprotected sex and poor treatment seeking among persons with disabilities compared to persons without disabilities (Stöpler, 2007; Mavuso and Maharaj, 2015). Therefore, to ensure that the SRH needs of persons with all kinds of disabilities have been addressed there is a need to explore the measurement of disability in the country and how various measures of disability relate to access and utilization of SRH services.

This study aims to explore the measurement of disability in Malawi and examine the link between the measurement of disability and access to SRH services. The study adopts a mixed methods approach comprising quantitative and qualitative components. In the quantitative component, two nationally representative surveys (2003 Malawi World Health Survey and the 2004 Malawi Demographic and Health Survey) have been combined to examine the relationship between the measurement of disability and utilization of SRH services. The two distinct datasets have been combined due to the limited information on the SRH of persons with disabilities. The quantitative analysis has been supplemented by a qualitative study, with a view to understanding how disability is conceptualised by the community members and operationalized in policies and programmes on SRH service provision. The study makes a substantial contribution to the understanding of disability and the SRH needs of persons with disabilities in Sub-Saharan Africa by providing the quantitative extent of the SRH service utilization problem. It also highlights disability issues that are not being addressed in the SRH programmes and policies of Malawi. The overarching goal is to inform efforts that aim at promoting the inclusion of persons with disabilities in SRH service policies and programmes.

1.2 Global estimates of persons with disabilities

Disability is a multidimensional phenomenon with no single definition. Its definition depends on the nature and severity of disability which often-times vary depending on the socio-cultural context of the population understudy (World Health Organization, 2002; Loeb, Eide and Mont,

2008). The multidimensionality of the disability concept implies that more complex, flexible measures of disability should be developed that will capture disability in all its manifestation (Loeb, Eide and Mont, 2008). The non-availability of a single definition of disability and the multidimensional aspect influences the estimation of persons with disabilities. Despite these influences, the existing data on persons with disabilities indicates that low and middle income countries have higher disability prevalence compared to high income countries (WHO and World Bank Group, 2011). Knowledge on the prevalence of disability is vital in this study because it provides evidence for focusing on the sexual reproductive health needs of persons with disabilities

Table 1.1:1 below provides the WHO and World Bank (2011) estimated prevalence of persons with disabilities. The estimates are drawn from the World Health Survey (WHS) which was conducted between 2002 and 2004 in 70 countries including China, Brazil and Malawi. The WHS survey collected disability information based on the International Classification of Functioning, Disability and Health (ICF) framework. The ICF framework conceptualise disability as "a dynamic interaction between health conditions and contextual factors that includes personal and environmental factors", (World Health Organization, 2011). The WHS survey collected disability data by focusing on the eight health domains of the activities and participation components of the ICF framework. The eight health domains included; affect, cognition, interpersonal relationships, mobility, pain and discomfort, sleep and energy, self-care and vision. The health domain of hearing was not included in the survey, even though it is a common impairment because it had low-endorsement rates in the general population. The hearing domain was also not included because it did not significantly contribute to the variation in health status of various sub-population groups (World Health Organization, 2011). Responses to questions relating to the eight health domains included: none, mild, moderate, severe and extreme difficulty in functioning. These responses were then used to calculate a composite disability score, ranging from 0 to 100, where 0 represented no disability and 100 represented complete disability. To differentiate persons with disabilities from persons without disabilities a cut-off point (or threshold) was created. A threshold of 40 on the scale of 0 to 100 was set to estimate the proportion of people who experienced significant difficulties in their daily lives (World Health Organization, 2011). A threshold of 50 was also set to estimate the prevalence of persons experiencing very significant difficulties in performing the eight health domains.

The results presented in table 1.2:1 indicates that approximately 15.6% of the world's population experience significant difficulties in carrying out their daily activities. In a world of more than 7 billion people, the disability prevalence implies that close to a billion people in both low and higher income countries have disabling conditions, with a higher proportion observed in low

income countries (18%). The table further indicates that the disability prevalence is higher (19.2%) among women compared to men (12%). Experiences of difficulties in carrying out daily activities are also more prevalent among people aged 60 and above (38.1%) and those living in rural areas compared to those on urban areas (16.4%). With regards to the economic status of the person with disabilities, table 1.2:1 indicates that disabling conditions are more prevalent among people in the lowest worth quintile (20.7%) compared to people in the highest worth quintile (11.0%).

There are a number of factors that are associated with the prevalence of disability in the world. These include demographic factors such as age, sex or poverty status and environmental factors such as earthquakes, wars or accidents. The age distribution of the population is said to be associated with the prevalence of disability in such a way that as a population ages, the prevalence of disability increases (World Health Organization, 2011; Guzman-Castillo *et al.*, 2017; Stephen Thompson, 2017). For example, Maria Guzman-Castillo et al (2017), in their study on disability and life expectancy on England and Wales, estimated that as the number of people aged 65 increases from 10.4 million (in 2015) to 12.4 million (in 2025) in England and Wales, the number of persons with disabilities will increase by 25% (i.e. from 2.25 million to 1.81 million). With regards to sub-Saharan Africa, the 2015 United Nations report on "Population Ageing", projects that the population aged 60 and above of sub-Saharan Africa will triple in size by the year 2050 (i.e. from 26 million in 1990 to 161 million in 2050). The increase in number of persons aged 60 and above implies that the proportion of persons with disabilities in the region will also increase. The projected increase in both sub-Saharan Africa and developed countries such as Europe in the old ages, will occur as a result of functional limitations which occurs due to the accumulation of health risks such as diseases, injuries and chronic illnesses. The risk of disability in sub-Saharan Africa is exacerbated with the high prevalence of infectious diseases and HIV/AIDS (Aboderin and Beard, 2015; United Nations, 2015b). This disabling effect of the infectious diseases and the growing number of persons with disabilities in the Sub-Saharan African region necessitates the need for addressing the sexual and reproductive health needs of persons with disabilities.

Apart from the ageing of populations, disability prevalence has also been found to be associated with the sex of the individual. Women in high, middle and low-income countries, have been found to have high rates of disabilities compared to men as shown in table 1.2:1. This is due to the fact that women tend to live longer than men, as such there are high proportions of women in the older ages compared to men. There are also high disability rates among women compared to men because they tend to suffer from disabling but non-life threatening conditions such as mild depression compared to men who suffer from diseases that have higher mortality rates (Murtagh and Hubert, 2004; Bora and Saikia, 2015; Wheaton and Crimmins, 2016). Even though women

tend to report higher levels of functional limitations and physical disabilities, not all disabling conditions are highly prevalent in women than men. For example, hearing loss is more prevalent among males (56%) than females (44%) (WHO and CBM, 2013).

Further to age and sex of the population, disability estimates have also been found to be associated with the poverty status of the people in the population of interest. There is a complex relationship between disability and poverty because not much research has been done to reflect the disability-poverty nexus. However, the available information on the association between disability and poverty indicates that poor people are more likely to experience disabling conditions compared to wealthy people (Groce *et al.*, 2011; WHO and World Bank Group, 2011; Stephen Thompson, 2017). For example, the WHO and World Bank estimates given in table 1.2:1, illustrates that in both higher incomes and lower income countries, people in the lowest wealth quintile (the poorest) have higher disabilities compared to people in the higher wealth quintiles (richest). The trend in the increase in disability with an increase in poverty status is observed in both the 40 threshold point and the 50 threshold point. Poor people have higher levels of disability compared to wealthy people, because of their increased risk of ill health due to their living in unsanitary and substandard housing (Groce *et al.*, 2011; Stephen Thompson, 2017). Poor people are also at increased risk of ill health that may lead to disabilities, because they lack access to clean water and have poor malnutrition status (Groce *et al.*, 2011). Poor people are also highly likely to live in areas where there are at increased risk of both physical and sexual violence. Poor people also have limited access to health care that can help reduce illnesses or injuries from becoming permanent disabilities (Stephen Thompson, 2017). The limited access to health care among poor people necessitates the need for providing health services including sexual and reproductive health services, to reduce the effect of sexually transmitted infections and fertility problems. Nonetheless, disability can also lead or exacerbate poverty due to the limited availability of economic activities that are tailored towards the needs of persons with disabilities.

In addition to the demographic factors, disability prevalence is also associated with environmental factors such as conflict or natural disasters and injuries. Conflicts are associated with disabilities because they cause injuries and trauma in the battle fields. Conflict also lead to health consequences due to the limited availability of emergency care, the breakdown of health and social services and the increased risk of disease transmission (Murray *et al.*, 2002; Stephen Thompson, 2017). Even though there are no definitive estimates of disabilities resulting from conflicts, WHO estimates that conflict account for 1.4% of the global disabilities (World Health Organization, 2011; Stephen Thompson, 2017). For example, the Human Rights Watch (2017) estimated that 250,000 people had disabilities due to the civil war or conflict in South Sudan. In Columbia, the decade's long conflict in the area is said to have left 200,000 victims, 2.5% of which

reported different types of disabilities (Biel Portero and Bolaños Enríquez, 2018). A survey on the impact of conflict on persons with disabilities among Syrian refugees in Jordan and Lebanon, has indicated that persons with disabilities in the refugee camps have limited access to services such as health care (including sexual and reproductive health), employment and education compared to persons without disabilities. Therefore, to ensure that the sexual and reproductive health needs of persons with disabilities in refugee camps are adequately addressed, there is a need for developing instruments that will accurately estimate the proportions of persons with disabilities.

Table 1.2:1 Disability prevalence rates for thresholds 40 and 50 derived from multi domain functioning levels in 59 countries, by country income level, sex, age, place of residence and wealth

Population subgroup	Threshold of 40			Threshold of 50		
	Higher Income countries (standard error)	Lower income countries (standard error)	All countries (standard error)	Higher income countries (standard error)	Lower income countries (standard error)	All countries (standard error)
Sex						
Male	9.1(0.32)	13.8(0.22)	12.0(0.18)	1.0(0.09)	1.7(0.07)	1.4(0.06)
Female	14.4(0.32)	22.1(0.24)	19.2(0.19)	1.8(0.10)	3.3(0.10)	2.7(0.07)
Age-group						
18-49	6.4(0.27)	10.4(0.20)	8.9(0.16)	0.5(0.06)	0.8(0.04)	0.7(0.03)
50-59	15.9(0.63)	23.4(0.48)	20.6(0.38)	1.7(0.23)	2.7(0.19)	2.4(0.14)
60 and over	29.5(0.66)	43.4(0.47)	38.1(0.38)	4.4(0.25)	9.1(0.27)	7.4(0.19)
Place of residence						
Urban	11.3(0.29)	16.5(0.25)	14.6(0.19)	1.2(0.08)	2.2(0.09)	2.0(0.07)
Rural	12.3(0.34)	18.6(0.24)	16.4(0.19)	1.7(0.13)	2.6(0.08)	2.3(0.07)
Wealth quintile						
Q1(poorest)	17.6(0.58)	22.4(0.36)	20.7(0.31)	2.4(0.22)	3.6(0.13)	3.2(0.11)
Q2	13.2(0.46)	19.7(0.31)	17.4(0.25)	1.8(0.19)	2.5(0.11)	2.3(0.10)
Q3	11.6(0.44)	18.3(0.30)	15.9(0.25)	1.1(0.14)	2.1(0.11)	1.8(0.09)
Q4	8.8(0.36)	16.2(0.27)	13.6(0.22)	0.8(0.08)	2.3(0.11)	1.7(0.08)
Q5(richest)	6.5(0.35)	13.3(0.25)	11.0(0.20)	0.5(0.07)	1.6(0.09)	1.2(0.07)
Total	**11.8(0.24)**	**18.0(0.19)**	**15.6(0.15)**	**2.0(0.13)**	**2.3(0.09)**	**2.2(0.07)**

[1]Note: The prevalence rates were standardised for age and sex. Countries were divided between low-income and high-income according to their 2004 gross national income (GNI) per capita. The dividing point was GNI of US$ 3255.

Source: (World Health Organization, 2011).

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1.3   Estimated proportions of persons with disabilities in Malawi

In Malawi, there have been slight variations in the estimated proportions of persons with disabilities in population censuses and surveys. This is due to the differences in the conceptualisation of disability and the purpose for collecting the disability data. For example, the 2008 population and housing census and the 2004 survey on "Living Conditions among People with Activity Limitations in Malawi", had different estimates of persons with disabilities. The 2008 population and housing census estimated the proportion of persons with disabilities to be 3.8% (NSO, 2008). The 2004 "Living Conditions among People with Activity Limitations in Malawi survey" on the other hand, reported an estimate of 4.2% (Loeb and Eide, 2004). The reported estimates of the "Living conditions survey, were different from the census   because the "living conditions study" collected disability data with the intention of developing a strategy and a methodology for collecting comprehensive, reliable and culturally adapted statistical data (Loeb and Eide, 2004). The 2008 Population and housing census on the other hand, collected disability data with the intention of establishing the prevalence of disability in the country (NSO, 2010a).

 For purposes of examining the link between the various measures of disability and the uptake of sexual and reproductive health services, this section focuses only on the "Living Conditions among People with Activity Limitations survey. This section focuses on the Living Conditions survey, because it collected disability data using the Washington Group Short set of questions. The Washington Group Short set of questions were developed based on the ICF framework which is a standard framework for collecting disability data that is comparable across countries.

 There have been two "Living Conditions among People with Activity Limitations surveys", that have been conducted in Malawi. The first survey was conducted in 2004 and a follow up survey was conducted in 2017. The two surveys, collected disability data based on the health domains of the activity and participation components of the ICF framework. The health domains included; sensory experiences, basic learning and applying knowledge, communication, mobility, self-care, domestic life, interpersonal behaviours, major life areas, community, social and civic life. Information on these health domains was collected on a six point response scale of 0 to 8. Where 0 represented no difficulty, 1=mild difficulty, 2=moderate difficulty, 3=severe difficulty, 4=unable to carry out the activity, 8=not applicable. The responses to the various domains were then scored to create an estimate of persons with disabilities. The estimated scores indicate that disability prevalence in 2004 was at 4.2% and in 2017 the rate was at 5.6 % (Loeb and Eide, 2004; Eide and Munthali, 2018) . The estimated prevalence of disability in Malawi in the two surveys is lower than the expected from the World Report on disability probably because the Washington Group Short Set of questions underestimate the true prevalence.

The results obtained from the 2004 and 2017 "living conditions survey" also indicate that there has been a 1.4% increase in the number of persons with disabilities between the two surveys. However, the increase in proportion of persons with disabilities has to be interpreted with caution. This is because the two surveys used two different instruments to screen the disabling conditions of persons aged less than 18 years, which is likely to have affected the overall outcome. The 2004 survey, used one screening tool to identify persons with disabilities among those aged less than 18 and those aged above 18; whilst the 2017 survey used two different disability screens. One disability screening tool was used to assess people aged 18 and above, and another screen was used to screen children who were aged less than 18 (Eide and Munthali, 2018). Use of one screening tool to identify both children and adults with disabilities, has been found to be a contentious issue among population researchers. This is due to the understanding that manifestations of disability in children is different from that of adults (Durkin, 2001; Cappa, Petrowski and Njelesani, 2015). Children may have some cognitive and hearing disabilities that may not be clearly identified by the standard disability screening tools. The use of one screening tool in the 2004 survey therefore, may have under-estimated the number of children with disabilities thus reducing the disability prevalence to 4.2%.

Further to the estimation of number of persons with disabilities in the 2004 and 2017 "Living conditions among people with activity limitations", the surveys also examined the causes of disability in the country. The results in the 2004 report, indicates that physical illnesses (48.3%) were the main underlying cause of disability in the country followed by congenital disabilities (disabilities that a person was born with) (17.2%) (Loeb and Eide, 2004). The 2017 results, indicates that illnesses and congenital causes continue to be the main causes of disability in the country with a proportion distribution of (57.9% and 27.2% respectively) (Eide and Munthali, 2018). The two causes of disability in the country may be as a result of the poor socio-economic development of the country as observed by Mitra et al (2013). Mitra et al (2013) in their study of disability and poverty in developing countries, found diseases to be the main contributing factor to the disability prevalence of poor countries including Malawi. Poverty is strongly associated with the incidence and prevalence of diseases which result into disability, because poor people often live in unsanitary and substandard housing. Poor people are also likely to be malnourished, lack access to water and are more likely to be involved in unsafe or dangerous jobs (Stephen Thompson, 2017). Poverty also has an increased likelihood of making a health condition to result into a disabling condition, particularly when there is a lack of health care services or barriers to accessing the services that are available (Mitra, Posarac and Vick, 2013). Therefore, the increase in disabilities that occur as a result of congenital and physical illnesses in Malawi, necessitates the

need for the provision of health services including sexual and reproductive health services to persons with disabilities.

With regards to provision of health services or uptake of health services to persons with disabilities, the "2004 Living conditions among people with activity limitations in Malawi survey," reports that more than 60% persons with disabilities were able to access health services. The 2017 survey on the other hand, reports that there has been an increase in the number of persons with disabilities who are able to access health services. The 2017 survey, reports that 77% of persons with disabilities were able to access health services during the study period. This demonstrates that there has been a 17% increase in access of health services among persons with disabilities between 2004 and 2017. However, there is no clear evidence of the type of health services that these persons with disabilities are accessing. The two surveys do not clearly indicate if the health services are those related to general illnesses such as Malaria, or maternal and child-health services or sexual and reproductive health services. Therefore, there is a need to examine the type of health services that persons with disabilities in the country are accessing, this is because they may not be receiving services that are essential for the reduction of further disabilities such as reproductive health services (WHO and UNFPA, 2009).

1.4 Problem statement

This study is predicated on the argument that universal access to SRH services among persons with disabilities is not a realistic goal to achieve in sub-Saharan Africa including Malawi because of the limited attention given to the measurement of disability. Other commentators including Daniel Mont and the 2010 World report on Disability, have argued that disability measurement affects the provision of services to persons with disabilities (World Health Organization, 2002; Mont, 2007a; Loeb, Eide and Mont, 2008; WHO and World Bank Group, 2011). Disability measurement poses challenges in service provision because it is contextually conceptualised and it requires development and adaptation of complex and flexible tools that will capture disability in all its manifestations (WHO and World Bank Group, 2011). This need for complex measures renders some approaches of disability measurement, such as impairment measures, to be inappropriate for the development of health service delivery programmes (Mont, 2007a; Palmer and Harley, 2012). For example, when designing an on-site program such as Voluntary Counselling and Testing (VCT) services for persons with visual impairments , knowledge on the number of people with visual impairments may be less important for service provision, than knowledge about whether they are able to travel to the centre to receive services (Mont, 2007a).

In Malawi, disability measurement issues arise not only from the complex nature of disability but also purposes for collecting disability data. Most disability studies that have been conducted in the country have collected disability data for other purposes rather than the provision of health services. For example, the 2008 Population and Housing Census (PHC) aimed at estimating the impairment levels of the population, as such disability was measured as an impairment in seeing, speaking, hearing, walking and climbing (NSO, 2010a). In the 2003 Malawi World Health survey, disability information was obtained for purposes of providing comparable health information on populations and health systems (World Health Organization, 2003). Disability in the 2003 Malawi World Health survey was measured as both an impairment and functional limitation (activity limitation and participation restriction). The implications of measuring disability as an impairment or functional limitation, is that disability is either underestimated or overestimated, and affect the development of policies relating to persons with disabilities, particularly policies relating to the provision of SRH services (Mont, 2007a; Loeb, Eide and Mont, 2008; WHO and World Bank Group, 2011). If disability is wrongly measured its nature and severity will not be clearly understood leading to inadequate delivery of SRH services since services will not be oriented towards the specific needs of persons with disabilities. As a result, persons with disabilities will remain in a situation of need.

1.5   Research objectives and questions

 The overarching goal of this study is to investigate the measurement of disability in Malawi and examine its relationship to SRH service utilisation. Specifically, the study aims to:

1. Explore how disability is conceptualised and how its conceptualisation influences the self-reported measurement of disability in Malawi

2. Examine how functional limitation and impairment measures of disability relate to access and utilization of SRH services

3. Explore how issues of disability are incorporated when implementing inclusive SRH policies and programs

The research objectives will be guided by the following research questions:

- How is disability conceptualised in Malawi?

- How do people's perceptions of health states relate to the self-reported measurement of disability?

- To what extent are measures of disability associated with the uptake of SRH services?

- How are issues of disability incorporated in Malawi's SRH policies and programmes?

1.6   The relevance of the study

Malawi is committed to providing comprehensive SRH services in line with various international and national agendas including the 1994 ICPD Program of Action that calls for universal access to SRH services. The Maputo Plan of Action, which provides a framework for achieving universal access to comprehensive SRH and Rights (SRHR) in Africa in the post-2015 period (African Union, 2006). The National Health Policy which aims at providing a comprehensive range of quality and equitable health services to all Malawians (Malawi Government, 2012; Ministry of Health, 2012). These international and national commitments can only be achieved by targeting vulnerable population groups such as the poor, young people and persons with disabilities who may be unable to access SRH services or programmes (Griffin, 2006; Wood, 2010). These population sub-groups, particularly persons with disabilities, are hard to identify due to lack of data on the number of persons living with disabilities and their SRH needs and experiences (Lee *et al.*, 2015; De Beaudrap *et al.*, 2016; ACFA, 2017). Therefore, by focusing on the measurement of disability in Malawi we seek to identify measurement approaches that can be used in estimating the proportion of persons with disabilities.

 Investigating access to sexual and reproductive health information and services among persons with disabilities also creates opportunities for challenging the social-cultural norms that contribute to the discrimination and stigma experienced by persons with disabilities when accessing SRH services. Persons with disabilities experience discrimination and stigma from service providers and community members when they are accessing sexual and reproductive health services such as contraceptive methods and antenatal care services (Munthali, Mvula and Ali, 2004; Mji et al 2008; World Health Organization, 2011) . The discrimination and stigma occurs due to the limited knowledge on the sexual and reproductive health needs of persons with disabilities among the health service providers and community members (World Health Organization, 2011). Persons with disabilities also lack knowledge on the contraceptive methods that are available at the local health facilities and on what needs to be done when pregnant or about to give birth (Munthali, Mvula and Ali, 2004). The lack of SRH knowledge among persons with disabilities and the lack of knowledge about the SRH needs of persons with disabilities among the community members and health service providers necessitates the needs to provide information and services to persons with disabilities. Therefore investigating access to SRH services among persons with disabilities helps to identify areas that needs to be prioritised when addressing discrimination and stigma experienced by persons with disabilities.

Examination of how issues of disability are being addressed in SRH policies and programmes in Malawi is also important, to determine if and how the policies address the SRH needs of persons

with disabilities (Kwadwo, Anafi and Sekyere, 2014). Persons with disabilities have the right to enjoy the highest attainable standard of health without discrimination on the basis of disability, therefore to ensure that their reproductive health rights are being met, national policies need to fully clarify their needs (Hendricks, 2007). Persons with disabilities are also at increased risk of acquiring sexually transmitted infections including HIV and AIDS due to their vulnerability to sexual violence and abuse and unsafe sexual behaviours (WHO and UNFPA, 2009; Mavuso and Maharaj, 2015). Therefore examining the inclusion of the SRH needs of persons with disabilities in national policies and programs helps determine the factors that contribute to the omission of the SRH needs of persons with disabilities in the national health policies and programmes.

1.7   Thesis Outline

The study starts by reviewing different materials on the conceptual understanding of disability, disability measurement issues, data limitations, and the relationship between SRH and disability. The aim is to link other study findings to the objectives of this thesis. The review chapter is followed by a discussion of the methods and sources of data used to address the study objectives. The fourth and fifth chapters presents results on the conceptual understanding of disability in Malawi. Chapter four discusses results obtained from an examination of self-reported disabilities, which include the use of anchoring vignettes and Compound Hierarchical Ordered Probit (CHOPIT) modelling. Chapter five presents results obtained from focus group discussions with community members in Malawi. The sixth chapter discusses methods used to address the limited availability of disability data in Malawi, particularly the use of a statistical matching technique where two distinct data sources are combined to produce a synthetic dataset of the variables of interest. A discussion has been drawn from this analysis that leads to the assessment of the link between disability and SRH services. Chapter seven presents an analysis of the relationship between impairment and functional limitation measures of disability and SRH services using logistic regression. A discussion drawn from the logistic regression analysis has led to the examination of how disability issues are addressed in SRH policies and programs in Malawi. The textual analysis of policies and programs on disability and SRH complements the outcomes of the measurement issues and the relationship between disability and SRH chapters. A conclusion on the key issues found in this study is drawn in chapter nine. The thesis ends with an assessment of what the study has accomplished through the investigation of disability measurement and how impairment and functional measures of disability relate to the uptake of SRH services. Finally, a comparative analysis of the study objectives against achievements is carried out to determine possible contributions of the research to the field of SRH and disability.

1.8 Conclusion

This chapter has given a brief background of the importance of the SRH services to persons with disabilities and issues relating to the measurement of disability in sub-Saharan Africa. The objective and the relevance of the study to the field of SRH and the achievement of national and international development agendas have also been discussed. Chapter two, outlines and discusses different research studies that have focused on disability measurement issues and the relationship between disability and SRH service utilization.

2 Chapter2: literature review

2.1 Overview

This chapter reviews studies and papers on the conceptual understanding of disability, its measurement and relationship to sexual and reproductive health services (SRH). The review focuses on both developed and developing countries, because persons with disabilities in both developed and developing countries face challenges when accessing SRH services. For example, in the United States of America (U.S.A) Becker et al (1997) found that women with physical disabilities were failing to access reproductive health services because of the structural barriers (such as physically inaccessible tables and stirrups) and the negative attitude of the service providers. The structural barriers and providers attitude are also some of the challenges that women with disabilities in Lusaka, Zambia face when accessing reproductive health services (Smith *et al.*, 2004) .

The review considers more than 25 articles from both developed and developing countries. The articles have been retrieved from the following search engines; Google, Google Scholar, PubMed, Web of Science and University of Southampton search engines (Webcat and Delphis). The following search terms were used: disability, measurement of disability and its prevalence, models and theories of disability, sexual and reproductive health of persons with disabilities, conceptual understanding of disability, and disability in Malawi and sexual and reproductive health of persons with disabilities in Malawi. Only articles published between 1990 and 2018 have been included in order to focus the research on current debates. In some cases, searches were conducted, using words referring to some specific aspects of sexual and reproductive health, such as family planning and disability, contraceptive use and disability, reproductive health and disability, and HIV and AIDS and disability. This was done to clearly understand how disability relates to various aspects of sexual and reproductive health services.

In reviewing studies and papers on disability and sexual and reproductive health, the chapter starts by discussing the conceptual understanding of disability in section 2.2. Section 2.3 discusses disability measurement issues focusing on impairment and functional measures of disability. This is followed by a review of data deficiencies on persons with disabilities and why this occurs, with reference to developing countries, especially Malawi. This section is followed by a review of issues surrounding disability and sexual and reproductive health. The chapter further reviews models that have been used to study the sexual and reproductive health of persons with disabilities.

These reviewed models provide a basis for this study's conceptual framework because they provide information on some of the factors that have been found to affect the utilization of sexual and reproductive health services among persons with disabilities.

2.2 Conceptual overview of disability

Disability is a complex phenomenon whose definitions or conceptualizations depend on the medical, economic, political and socio-cultural climate surrounding its conceptualization (Loeb, Eide and Mont, 2008; WHO and World Bank Group, 2011). At times disability is conceptualised in relation to any pathology of the human body, but sometimes its conceptualization encompasses a mix of personal and environmental factors. The dependency of the concept of disability on climatic conditions has made it into a contentious issues such that there is no universally agreed definition of disability. Since the concept of disability has been a contentious issue, this section provides a brief overview of its conceptualization.

In terms of the medical conceptualization, the World Health Organization (WHO) published the International Classification of Impairment, Disabilities and Handicaps (ICIDH) in 1980, which described disability as any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being (World Health Organization, 1980; Whiteneck, 2006). This perspective sparked controversy among social researchers and disability organizations because it failed to incorporate the influence of environmental factors (Jette, 2006; Whiteneck, 2006). Twenty-one years later, the WHO changed its conceptualisation of disability from a medical to a biopsychosocial perspective where disability is now conceptualised as a negative interaction between a person with a health condition or an impairment and features of the environment in which the person lives (World Health Organization, 2002; Whiteneck, 2006). The biopsychosocial perspective incorporates the influence of environmental factors and has led to the revision of the ICIDH as the International Classification of Functioning, Disability and Health (ICF). The revised ICF classification system which incorporates the influence of environmental factors has been universally accepted by both disability advocacy groups and researchers, as well as being regarded as a clinical problem-solving tool in physical therapy and rehabilitation medicine (Steiner *et al.*, 2002; Whiteneck, 2006).

Further to the medical perspective, disability has also been conceptualised in relation to the welfare or charity model. In this model, health and social researchers have described disability as a condition that enables a person to be eligible for various forms of assistance and aid. This perspective implies that disabilities can be cured by medicine and leads to the understanding that any person with a pathology, however severe it may be, qualifies for social aid and

accommodation regardless of the level of functioning (Masala and Petretto, 2008; Alycia Reppel, 2014). Social researchers, in particular economists, view disability in relation to a person's inability to participate in work. Disability in this capability approach refers to the degree to which impairment affects an individual's productivity and its economic consequences to the individual, employer and the state (Mitra, 2006). This capability view of disability identifies persons with impairments for state welfare benefits.

Persons with disabilities have also had their own conceptualizations of disability which have focused on the achievement of inalienable rights and measures for safeguarding against marginalization and stigma. This perception of disability in relation to marginalization and stigma has been coined the social model of disability.   For example, disability activists in the Union of the Physically Impaired against Segregation (UPIAS) in the United Kingdom understand disability as a social construct (Oliver, 1996; Mitra, 2006; Masala and Petretto, 2008). To them, disability is not caused by a person's impairment but rather society's failure to provide appropriate services and adequately ensure that the needs of persons with disabilities are taken into account in a societal organization (Oliver, 1996). This perception of disability aims to remove barriers that restrict life choices for persons with disabilities. In the United States, disability activists understand disability in relation to the oppression of minority groups. For example, Mitra (2005) explains that persons with disabilities face discrimination and segregation through sensory, attitudinal, cognitive, physical and economic barriers and their experiences are similar to those of oppressed minority groups. Even though persons with disabilities experience discrimination which may be similar to that of minority groups, their individual experiences of discrimination and stigma differ in relation to the type of impairment, age, gender and place of residence (Terzi, 2005; Mitra, 2006). For instance, a person with a disfigurement due to leprosy may experience stigmatization that relates to interpersonal relationships whilst a person who uses a wheelchair may experience discrimination that relates to the built-in environment such as lack of ramps in buildings.

In addition to disability being conceptualised depending on the medical or social climate, the cultural context of a population understudy also contributes to the understanding of disability. The culture context plays an important role in the conceptualization of disability because in many societies, particularly those in sub-Saharan Africa, social interdependence and individual's role within the larger family and community, contribute to people's understating of disability and its aetiology (Groce, 1999; Groce, 2006; United Nations, 2016; Baxter C. and Mahoney W. , 2018). Cultural beliefs also contributes to the community members' attitude towards persons with disabilities, and their health seeking behaviour (Baxter C. and Mahoney W. , 2018). The cultural understanding or beliefs towards disability also influences the relationship between persons with

disabilities and the health professionals. Therefore, if there are misconceptions or social constructions concerning the causes of disability, persons with disability may experience stigma and discrimination when seeking sexual and reproductive health services. Therefore, to comprehensively address the sexual and reproductive health needs of persons with disabilities, it is important to examine the cultural understanding of disability within a particular society.

There are variations in the cultural understandings of disability within and across countries. For example, in the United States, a complete male person is portrayed as young, married, college educated, of good complexion, weight and height and a recent record in sports; therefore any damage to the physical, intellectual or emotional nature is interpreted as a disability (Groce, 1999; Holzer, Vreede and Weigt, 1999). Disability is thus understood as a difference that prevents a person from fully participating in life without the assistance of others or technology.

In the Middle East on the other hand, the understanding of disability is influenced by both culture and religious beliefs such as the Islamic faith. Culturally, disability is perceived as a blessing but also a curse in some societies (Al-Aoufi, Al-Zyoud and Shahminan, 2012). For example, in Afghanistan, disability is viewed "as a medical problem or one brought by divine punishment or a person's bad luck, which can only be removed through either medical or religious intervention", (Coleridge, 2000). Such attitudes make it difficult to implement community-based rehabilitation programmes because such programmes do not offer any cure for disability. In cultures where disability is viewed positively, disability is understood as a natural part of human nature and a source of blessings from Allah or God. For example, in Damascus, Umayyad Caliph al Walid ibn Abd al-Malik established a care home for persons with intellectual disabilities because of the perception that it is a blessing to take care of persons with disabilities (Aljazoli, 2004).

Apart from the Middle East, Asia and the Pacific regions also have their own understanding of disability, based on their traditional beliefs and practices (UNDP, 1997; Takamine, 2004). In Cambodia and Thailand, community members understand disability as punishment for family misconduct or as karma (Takamine, 2004). This traditional belief makes the parents with children with disabilities feel the need to hide these children at home, in order to prevent them from taking any risks. In the Pacific region, particularly Fiji, children or persons with disabilities are viewed as people who have no capacity to develop themselves in terms of intellectual and physical capacities (UNDP, 1997). Such negative perceptions produce low expectations for persons with disabilities, which in-turn lead to the low participation of persons with disabilities in education and employment and reduce their access to financial and health services.

With regards to sub-Saharan Africa, there are many similarities in the understanding of disability across the sub-Saharan Africa region, particularly in relation to the cause of disability (Agbenyega,

2003; Stone-MacDonald and Butera, 2014; Bunning *et al.*, 2017). Disability, in most sub-Saharan African communities, is understood as a punishment for bad deeds committed by the parents or the result of witchcraft exercised by other people (Stone-MacDonald and Butera, 2014). For example, in Ghana, particularly in rural settings, pregnant women are not allowed to eat eggs for the reason that the child might develop hydrocephalus (Agbenyega, 2003). Therefore, when a child is born with any defect, it is seen as a punishment for violating such traditional beliefs. In Kenya, among the Giriama culture, married couples are not expected to indulge in extra-marital affairs when the woman is pregnant because of the belief that couple behaviour during pregnancy affects the child (Bunning *et al.*, 2017). Therefore, when a child is born with an obvious defect it is seen as punishment for the sins committed during pregnancy. These examples illustrate the similarities in the understanding of disability, particularly as a punishment for past deeds committed by the parents of the person with a disability.

In Malawi, disability is perceived from a biological and traditional perspective. In terms of biology, most types of disabilities in Malawi such as sensory and physical disabilities are perceived to be caused by biological factors. In-terms of sensory disabilities such as visual impairments, a high proportion of community members believe that visual impairments are caused by infections such as conjunctivitis and having a sore in the eye (Munthali, Mvula and Ali, 2004). In terms of physical disabilities, the understanding is that physical impairments such as paralysis is caused by congenital diseases and polio. With regards to traditional beliefs, there is an understanding in the country that sensory and physical disabilities are caused by witchcraft. Witchcraft causes physical disabilities such as paralysis in such a way that a witch mixes sand, the footprint of a persons and traditional medicine. When these three things mix, a person start experiencing mobility problems. With regards to albinism, the traditional belief in Malawi is that a person is born with albinism because when his mother was pregnant she did not spit on the ground when she looked at an individual with albinism (Braathen and Ingstad, 2006; Munthali, 2011).

Although the understanding of socio-cultural beliefs and practices towards disability is relevant for developing and implementing programmes for persons with disability, they should not be viewed as static (Groce, 1999; United Nations, 2016). They change over time especially when they intersect with western ideas. Most populations in developing countries including Malawi are now exposed to disability awareness programmes that are either conducted in their communities or aired on radio, television, movies, magazines and newspaper (Groce, 1999; Wegner and Rhoda, 2015; Bunning *et al.*, 2017). The information obtained from these programmes, when combined with the old ideas produce hybrids that are neither wholly the old nor the new socio-cultural systems, but transforms people's attitude towards disability (Groce, 1999). For example, in

Zimbabwe "young campaigners with disabilities went on a speaking tour of six secondary schools, reaching over 12,000 school children over the course of two months", (United Nations, 2016). This campaign resulted in the transformation of schoolchildren and their teachers' attitude towards disability. These results demonstrate that socio-culture beliefs and practices change, therefore when studying community members' understanding of disability care must be taken to ensure that local beliefs and practices are not viewed as static.

To sum up, there are different conceptualisations of disability i.e. based on a person's impairment and the surrounding environment, pathology and socio-welfare benefits. Disability can also be conceptualised in an effort to address the social oppression that persons with disabilities face due to the unaccommodating environment. The socio-cultural context of a population also influences people's understanding of disability. The different conceptualisations of disability have implications, they influence the estimation of the number of persons with disabilities and the implementation of sexual and reproductive health service programmes. For example, when people conceptualise disability as a condemnation of past sins, they may not report their household members who have disabilities because of fears of being looked down on by their fellow community members (De Beaudrap *et al.*, 2016) .

 Differences in the conceptual understanding of disability may also affect implementation of SRH programmes because of differences in the understanding of the target population (Groce, 2006; Mont, 2007a). For example when the community members understand disability as an impairment, they may encourage only those with visible impairment to access the services, thus neglecting those with invisible disabilities such as intellectual disabilities. With regards to Malawi, little is known about the conceptual understanding of disability. The few studies that have looked at persons with disabilities have observed that persons with disabilities are perceived as beggars or people who cannot be employed or take care of themselves (Munthali, Mvula and Ali, 2004; Mji et al 2008). In relation to this study, little is known about the relationship between the conceptual understanding of disability and the self-reporting of disability. Therefore, this study aims to explore the conceptual understanding of disability and examine its relationship to self-reported disabilities.

2.3   Measurement of disability

The measurement of disability during population censuses and surveys has been conducted ever-since the onset of population censuses. However, the demand for robust disability estimates has increased due to the proclamation of the International Year of Disabled Persons (1981) and the recently adopted 2006 Convention on the Rights of Persons with Disabilities (CRPD) (United

Nations, 1983;1994; Hendricks, 2007; Palmer and Harley, 2012). The measurement or collection of disability data during population censuses and surveys is important for development of inclusive policies and programmes (Palmer and Harley, 2012). Disability data is also important for monitoring of the functioning status of populations and the assessment of the equalization of opportunities. For developing countries like Malawi, disability data is required to optimally target the limited resources (WHO and World Bank Group, 2011; Palmer and Harley, 2012). Therefore, to collect disability data that can be used to optimally target the limited resources, social and health researchers have developed instruments that are used to collect information about persons with disabilities.

The instruments for collecting disability data include the 36 Item short form survey and the index for Activities of Daily Living (ADL) (McDowell, 2006; Palmer and Harley, 2012). Even though a number of instruments have been developed to collect disability data, there are three main approaches of collecting disability data. The three approaches depend on what the information on disability is needed for. The first approach of measuring disability data is direct questioning where a participant is asked if they have a disability (WHO and World Bank Group, 2011). The second approach is the use of functioning screens that focuses on the activity limitation and participation restriction (Mont, 2007a). The third one are clinical impairment measures of disability, where a participant is asked to perform a specific task that relates to an impairment such as visual impairment or a health condition such as depression (Mactaggart *et al.*, 2016). The following paragraphs discusses the direct questioning, functioning and clinical impairment measurement approaches of disability during population censuses and surveys.

2.3.1   Direct questioning approach

Direct questioning approaches are developed based on the understanding that disability results from a person's impairment or medical condition (Palmer and Harley, 2012). During population censuses or surveys, a participant may be asked if there is someone in the household who has a disability; or in other cases, it may be about the presence or absence of handicaps. In the most simplistic form, disability can be measured by asking: "Do you/does (*name* have a disability? Yes/No (Mbogoni, 2003). In some instances, this question may be followed by a list of severe impairments such as blind, deaf, physical disability or mental retardation. This approach of measuring disability has been practised mostly in Africa, Asia and South America; and in most cases, it has produced disability estimates that are below 3% (United Nations, 1990; Mbogoni, 2003). For example, in Thailand, the use of the direct questioning; ' is (name) disabled?' produced a disability prevalence of 0.3% (United Nations, 2017).

Direct questioning is an ideal measure of disability for inclusion in population censuses that can only incorporate a few relevant disability questions given the large scale of data collection (WHO and World Bank Group, 2011). Despite being an ideal measure, direct questioning has been criticised by social researchers and disability advocacy groups (Mbogoni, 2003; Mont, 2007a; WHO and World Bank Group, 2011; Palmer and Harley, 2012). Social researchers argue that direct questioning is not an adequate measure of disability because it mainly focus on severe cases of disability such as blindness (WHO and World Bank Group, 2011; Palmer and Harley, 2012). Furthermore, direct questioning fails to incorporate the impact of personal and environmental factors on a person's functioning, in particular their activity and social participation. The use of the word "disability" in direct questioning has also been criticised because of the cultural beliefs that are associated with disability, such as punishment from past sins (Mont, 2007a; Loeb, Eide and Mont, 2008; Palmer and Harley, 2012). These cultural beliefs make people to feel ashamed in identifying themselves as having a disability. The inability of a person to self-report or report other family members as having a disability lowers estimates of disability. Therefore, single questions on disability should be avoided as they will underestimate the true prevalence. Nonetheless, self-reported or direct question measures are ok, as long as they are in more depth than one item question (Mactaggart *et al.*, 2016).

With regards to this study, persons with disabilities in the 2003 Malawi World Health Survey (MWHS-2003) were also estimated using direct questioning. However, instead of asking the participants whether or not they have a disability, the research assistants observed their participants and recorded if the participant had an impairment. This approach of collecting disability data helps reduce the errors that occur due to a participant understanding of disability, but may be affected by the research assistant's understanding of disability. To correct for any bias that may be introduced by a research assistant's understanding of disability, the survey also collected data on disability using functioning measures.

2.3.2   Functioning measures or screens

Disability can also be measured using functioning screens. Functioning screens differ from direct questioning because they focus on activity limitation and participation restriction (Mont, 2007a; Palmer and Harley, 2012). The difference in focus is based on the understanding that disability limits a person from carrying out their daily activities or participating in social activities like education (Mont, 2007a; WHO and World Bank Group, 2011). Functioning measures or screens are developed either to address the needs of a specific population group, such as the elderly or chronically ill patients, or to provide an internationally comparable instrument for measuring disability.

There are a number of functioning screens that have been developed to measure disability, including the WHO Disability Assessment Schedule 2.0 (WHODAS 2.0), Washington Group Short set of questions, the Index of Activities of Daily Living (ADL), Model disability survey and the 36 Item Short Form Health Survey (SF-36) (Ware Jr, 2000; McDowell, 2006; Mont, 2007b; World Health Organization, 2015b) . To provide an overview on how functioning screens measure disability, the WHODAS 2.0 and the KATZ index of Activities of Daily Living, the Model Disability survey and the Washington Group Short set of questions will be discussed.

2.3.2.1   WHO Disability Assessment Schedule 2.0 (WHODAS 2.0)

The WHO Disability Assessment Schedule 2.0 (WHODAS 2.0) is a disability assessment tool that was developed by the World Health Organization. The WHODAS 2.0 was developed with the aim of addressing the need for a generic cross-cultural measurement tool for assessing health and disability at the population level or in clinical practice (Üstün, 2010; Üstün *et al.*, 2010). WHODAS 2.0 was developed to also address the limitations of the original 1988 WHO Disability Assessment Schedule (WHO/DAS), which mainly focused on the functioning of psychiatric patients and failed to address the influence of the socio-cultural context of the individual (Üstün *et al.*, 2010). The WHODAS 2.0 is based on the WHO's ICF Framework, but mainly corresponds to the Activity and participation domains of the ICF framework. The WHODAS 2.0 captures individual functioning in six domains: (1) cognition (understanding and communication); (2) Mobility (moving and getting around); (3) self-care (attending to one's hygiene, dressing, eating and staying alone); (4) getting along (interacting with other people); (5) life activities (domestic responsibilities, leisure, work and school); (6) Participation (joining in community activities, participation in society) (Üstün, 2010; Üstün *et al.*, 2010). To estimate the proportion of persons with disability, the responses to the six health domains are scored and used to create a disability scale which ranges from 0 to 100 where 0 represent good health and 100 relates to poor health or disability. To ascertain the prevalence of disability a threshold of 40 or 50 is set on the disability scale, such that all the participants whose total score is less than the threshold point (below 40) are classified as not having a disability and those whose score is above the threshold point (above 40) are classified as having a disability.

The WHODAS 2.0 is a reliable measure of functioning and disability and is applicable across cultures in all adult populations because it examines the main health problems experienced by people aged 18 and above (Üstün, 2010). The reliability and applicability of the WHODAS 2.0 have led to its use in Multi-country surveys (World Health Organization, 2003), dementia studies (Konecky *et al.*, 2014), clinical trials and rehabilitation studies (Hanga, DiNitto and Leppik, 2016).

Even though the WHODAS 2.0 is a useful measure of functioning, it has been observed to pose some problems in the measurement of disability (Kulnik and Nikoletou, 2014; Chang *et al.*, 2015; Marx *et al.*, 2015; Habtamu *et al.*, 2017). For example, in assessing veterans with the post-traumatic disorder, Marx et al (2015) observed that WHODAS 2.0 does not have a means to measure severe symptoms of post-traumatic disorders. Habtamu et al (2017) have also observed that the household activities domain of the WHODAS is not compatible with the African socio-cultural context, particularly in rural areas, where domestic activities such as grocery shopping and cooking are perceived to be a woman's responsibility. The other limitation of the WHODAS 2.0 that has been observed by researchers, is its failure to capture the influence of physical disabilities and environmental factors which are not included in the activity and participation domain of the ICF Framework (Kulnik and Nikoletou, 2014; Chang *et al.*, 2015). For example, in investigating the generic patient-reported measure of disability, Kulnik et al (2014) had trouble in measuring the impact of social and environmental barriers such as the provision of care and parking facilities.

2.3.2.2   The index of Activities of Daily Living (ADL)

The index of Activities of Daily Living is another functioning screening that measures disability through activity performance (McDowell, 2006). Sidney Katz developed it in 1959 and he later revised it in 1976. It was initially developed to study the functioning of elderly and chronically ill patients, but has now been extended to the evaluation of health care treatments, health care utilization, home care and insurance coverage (McDowell, 2006; Fisher, 2008). The index of ADL was originally developed to measure the level of functioning or performing in the following six domains: bathing, dressing, using the toilet, transferring from the bed to the chair, continence and feeding (McDowell, 2006). In the 1970s, the index was upgraded to the measurement of higher-level activities such as shopping, cooking and managing money. The ADL thus measures activity limitations and participation restrictions experienced by an individual. If there are some mild or moderate impairments or health conditions such as mild depression that do not influence an individual's activities or participation then those impairments or health conditions are perceived as not being disabling. To estimate the proportion of persons with activity limitation and participation restrictions, responses to the ADL questions are scored and a threshold is set as explained in section 1.2 on the global estimates of disability. Unlike the WHODAS 2.0 that does not incorporate the influence of contextual factors, the index of ADL measures the influence of contextual factors such as economic status, culture and physical environments (Palmer and Harley, 2012). The incorporation of contextual factors in the ADL index has led to the perception that it is a good measure of disability compared to the WHODAS 2.0. This is because

environmental factors, such as absence of ramps in buildings, may affect the mobility of persons with disabling conditions.

Despite being acknowledged as a good measure of functional disability that incorporates the influence of contextual factors, the ADL index still has some limitations. It does not measure minor disabilities such as mild visual impairments or hearing loss, because they do not translate into limitations of ADLs such as bathing or dressing (McDowell, 2006). The index of ADL also fails to capture small changes in the functioning of the chronically ill or the elderly, and as such it is not an appropriate measure for health surveys or clinical trials (Fisher, 2008). The index of ADL measures disability on a dichotomous scale of yes or no. This dichotomous scale is problematic because it loses information on the variability of the responses (McDowell, 2006). The index of ADL is also limiting because it cannot estimate the prevalence of disability unless a threshold is set. The other limitation of the ADL relates to its focus of measurement, which is on what an individual cannot do or has trouble in performing. This approach of measurement is limiting because it fails to collect information on how the participants view themselves and what kind of daily activities the participants value most (Palmer and Harley, 2012).

2.3.2.3   The Washington Group Short Set of Questions on Disability

The Washington Group Short Set of questions (WGSS) is another functioning screen that identifies people with disabilities during population censuses and surveys. This functioning screen was develop by the Washington Group (WG) on Disability Statistics with the purposes of developing policies and programmes that guide in the provision of services to persons with disabilities (Madans, Loeb and Altman, 2011; Loeb, 2016). The Washington Group Short set of questions was also developed to monitor the level of functioning in various populations and to assess the equalization of opportunities. Developed based on the bio-psychosocial model of disability also known as the International Classification of Functioning, Disability and Health (ICF) framework, the Washington Group Short Set of questions measures disability by identifying people who experience difficulties in walking, seeing, hearing, cognition, self-care and communication(Madans, Loeb and Altman, 2011). These set of questions measure disability using the six core domains of the activity and participation components of the ICF framework.

The Washington Group Short set of questions was purposely developed to be used in population censuses that can only incorporate few relevant questions. So far, the Washington Group Short set of questions has been used in 69 national censuses and it yet to be included to an additional 29 national censuses (Groce and Mont, 2017). In the 69 population censuses, the WGSS has been found to not only measure the presence or absence of disability but also the type and severity of

disability. The results obtained from the WGSS have also been found to be comparable within and across populations. However, just like any another measurement tool, the Washington Short Set of Questions has some limitations. One of its limitations is that it does not fully capture information on mental health impairments such as fatigue (Madans, Loeb and Altman, 2011). The WGSS also does not comprehensively collect information on the disabling condition of children especially those aged below 5, thus it significantly misses information on development or psychosocial impairments of young children (Loeb, 2016; Groce and Mont, 2017). To address some of the WGSS limitations, the Washington Group on Disability Statistics has developed a child set of questions.

An extended version of the disability measurement tool has also been developed that can be used in surveys which have enough time and resources. The extended version of the Washington short set of questions collects additional information on upper body functioning, psychosocial difficulties and domains on functioning with and without the use of assistive technology or aids (Madans, Loeb and Altman, 2011; Loeb, 2016; Groce and Mont, 2017).   The extended set of questions also collects information on the age at the onset of disability and the impact of disability on people's lives.

Further to the extended version, information on psychosocial difficulties and the impact of disability on people's lives together with other disability questions from both national and global surveys such as the WHO multi-country survey have led to the development of the Model disability survey. The Model disability survey is a general population survey that provides detailed information on the lives of persons with disabilities. This model survey was developed by the World Health Organization and the World Bank in collaboration with the Washington Group on Disability Statistics (Sabariego, 2017; World Health Organization, 2019). This survey is based on the ICF framework and signifies an evolution in the concept of disability measurement. In comparison to other disability surveys such as the World Health Survey, the Model disability survey is an improvement to the old disability surveys, because it does not identify persons with disabilities through the probing of difficulties in carrying out daily activities. The model identifies persons with disability by asking people what they do and do not do in their lives (Sabariego, 2017). These type of questions are vital in disability research because they highlight the functioning of people in multiple domains given the environmental barriers and facilitators that constitute their real life situation.

The other advantage of the Model disability survey is that it allows researchers and policy makers to directly compare the living conditions of people with different levels of disability and also comparison between those with disabilities and those without disabilities(World Health

Organization, 2019). Through such comparisons policy makers are able to identify interventions that maximizes the inclusion and functioning of persons with disabilities. Nonetheless, the collection of disability data through asking participant what they do or do not do, poses challenges to disability data because the study participants need to be guided to not think about what they cannot do because they are paralysed or depressed but about what their lives are like (Sabariego, 2017). Such kind of thinking is likely to be affected by the participant's contextual background. The other limitation of the Model Disability survey is that it is very long as such it is time consuming and is likely to be affected by response errors due to respondent's fatigue.

2.3.3   Clinical impairment screens

A clinical impairment screens is another approach of measuring disability during population surveys. This approach focuses on determining whether the study participant has an impairment or any health condition that affect "the body function and structure "component of the ICF framework (Mactaggart *et al.*, 2016). An impairment is an abnormally in body function and structure such as significant deviation or loss in hearing. Therefore, impairment screens are disability measures (often clinical or objectively) of abnormalities in body functions or structures. Impairment screens usually rely on clinical assessment such as visual acuity screen or time up and go. They also measure psychological conditions such as depression and respiratory conditions such as asthma (Mactaggart *et al.*, 2016) Impairment screens also require the presence of a clinician or health experts such as a nurse and a medical equipment as a result they are not recommended for population censuses. For example, when using a time up and go screen, clinical examiner or specialist may assesses the mobility impairment of study participant by she or her to transfer from sitting to standing, walk a distance of 3m, turn around and walk back and transfer from standing to sitting at a comfortable speed (Rao *et al.*, 2009). Through this measurement approach the clinician determines the severity of the mobility problem experienced by the study participant.

The advantage of using impairment screens during disability surveys is that the help determine the cause and severity of the impairment or health condition. The information on the cause or severity of the impairment helps policy-makers or programme-developers to develop target specific programmes that adequately addresses the needs of persons with disabilities. Nonetheless, it is not adequate to use clinical impairment screens alone during population surveys, because they do not capture information on how the study participant functions in his or her environment (i.e. activity limitation and participation restriction) and his or her overall disability experience (Mactaggart *et al.*, 2016). The other limitation of clinical impairment screens

is that they uses clinical examiners and specialist equipment's that only focuses on one impairment. The focus on one impairment and use of clinical examiners or expertise is expensive for disability surveys because a single disability survey objectively measures a number of disabling conditions or impairments.

With regards to this study, measuring disability as an impairment may be of value because of the understanding that disability results from impairments or health conditions. Nonetheless, it is vital not only to estimate the number of persons with impairments, but also to understand whether or not the persons with impairments are able to access the services. Therefore, an inclusion of functional measures of disability may help determine the number of persons with impairments that may experience mobility or any other bodily discomforts when accessing the services. In addition to measuring the mobility limitations that persons with impairments or health conditions may face, it may also be relevant to examine the effect of disability on the economic productivity and the sexual and reproductive health of persons with disabilities. Such information may help policy makers to understand the impact of disability on a person's sexual and reproductive health but also on their economic productivity. However, it is rare to collect disability information using all three approaches in one survey, because it is costly to use three different instruments (Mont, 2007a; WHO and World Bank Group, 2011). Therefore, a survey with two of the three approaches is sufficient to provide information for addressing the SRH needs of persons with disabilities. This study therefore, aims to examine the measurement of disability using impairment and functioning screens because they are the main measurement approaches that were used in the 2003 Malawi World Health Survey.

In summary, this section has acknowledged that there are different approaches for measuring disability. Disability is measured using impairment screens where study participants are asked if they have a disability or whether any member of the household has a disability. Disability is also measured using functioning screens that focus on the level of difficulty experienced by a participant when carrying out daily activities such as moving around or dressing. The section has further explained that disability can be measured using weighting scales where disability is measured based on the number of years lost due to disability. All these disability measurement approaches affect the estimation of the number of persons with disabilities because of their focus or target populations.

2.4 Data limitations on the sexual and reproductive health needs of persons with disabilities

There has been growing evidence of the availability of disability data in sub-Saharan Africa, however reliable data to determine the sexual and reproductive health behaviour of persons with disabilities is not readily available (Mont, 2007a; Loeb, Eide and Mont, 2008; WHO and World Bank Group, 2011). In countries where disability data is available, there are disagreements concerning the estimated number of persons with disabilities among researchers and the communities of persons with disabilities For example, in Zimbabwe the 1997 Inter-Censal Demographic Survey estimated the number of children with disabilities to be 57,232, within the same year the United Nations International Children's Emergency Fund (UNICEF) estimated the number of children with disabilities to be 150,000, a number that was 3 times higher than the Inter-Censal Demographic survey estimate (Rusinga, 2012). This created confusion among researchers and data users. Smith et al (2004) also report that in Zambia, national disability organisations do not agree with the Zambian national census estimates. Disability organisations believe that the national census results underestimate the total population of persons with disabilities (Smith *et al.*, 2004). These discrepancies and non-availability of information on the sexual and reproductive health of persons with disability in the region create difficulties in studying the sexual and reproductive health of persons with disabilities, particularly in classifying populations of interest and in identifying the most disabling conditions.

Substantial efforts have been made by the global community in the past two decades to address the problem of limited disability data in sub-Saharan Africa (World Health Organization, 2002; Loeb, Eide and Mont, 2008; WHO and World Bank Group, 2011). The United Nations through the Washington Group on Disability statistics have developed a short set of disability questions to be used in censuses and surveys (Mont, 2007a; Loeb, Eide and Mont, 2008). This short set has been piloted in a number of countries including, Zimbabwe and Zambia and has been used to collect disability data in 69 national population censuses (Loeb and Eide, 2004; Loeb, Eide and Mont, 2008). In Malawi, the Washington Group Short set of questions has been used to collected disability data in two nationally representative surveys called "Living conditions among people with activity limitations. The two surveys have been used to discuss the disability prevalence of Malawi in section 1.3 of the introductory chapter. Other researchers including De Beaudrap et al (2015) in Cameroon, have adopted a life-course approach to study the vulnerability of persons with disabilities to HIV and other sexual and reproductive health problems.

Even though a number of efforts have been made to improve the availability of disability data, there still exists problems with data on the sexual and reproductive health of persons with disabilities since not much information on sexual and reproductive health can be collected during population censuses. However, in resource-constrained countries like Malawi, conducting a census or survey that specifically focuses on the sexual and reproductive health needs of persons with disabilities may not be a feasible solution due to budgetary constraints. Moreover, there are a number of sexual and reproductive health surveys including the Demographic and Health Surveys (DHS) and Multiple Indicators Cluster Surveys (MICS) that are being conducted in the region, that collect information that is similar to that collected in disability surveys. Therefore, to reduce the cost and response burden, these available data sources may be used to study the sexual and reproductive health of persons with disabilities.

This study therefore proposes the use of statistical matching, a technique used by practitioners to combine information from distinct data sources referred from the same target population, as a solution for addressing the limited disability data problem that the sub-Saharan African region is experiencing (Moriarity and Scheuren, 2001; D'Orazio, Di Zio and Scanu, 2006). This is a good solution because it combines variables that have not been jointly observed. Statistical matching can also be used in situations where detailed information for a particular topic entails development of long questionnaires, which tend to have a low response quality and a high frequency of missing responses (Rubin, 1986; D'Orazio, Di Zio and Scanu, 2006).

2.5   A review of access to sexual and reproductive health services among persons with disabilities

2.5.1   Defining sexual and reproductive health

Sexual and reproductive health is a term coined by the global community during the 1994 International Conference on Population and Development (ICPD) , it refers to "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, in all matters relating to sexuality, the reproductive systems and its functions and processes", (UNFPA, 2014 p.25). Sexual and reproductive health ensures that men and women access safe, effective, affordable and acceptable methods of family planning, which are not against the law. It also ensures that men and women access appropriate health care services that will enable women to go through pregnancy and childbirth and provides couples with the best chance of having a healthy infant (Glasier *et al.*, 2006; UNFPA, 2014). It also enables people of all ages to experience safe and satisfying sexual relationships by reducing incidences of gender

discrimination, inequalities in accessing health services, sexual coercion, exploitation and gender-based violence (Glasier et al., 2006).

Sexual and reproductive health services involve the provision of reproductive health care and sexual health. These services include, improvement of antenatal, perinatal, postpartum and new-born care; provision of high quality services of family planning, including infertility services; elimination of unsafe abortions; prevention and treatment of sexually transmitted infections, including HIV, reproductive tract infections, cervical cancer, and other gynaecological morbidities; and promotion of healthy sexuality (Glasier et al., 2006; Fathalla and Fathalla, 2008; UNFPA, 2014). Provision of sexual and reproductive health services, particularly family planning methods is important because it reduces the number of unintended pregnancies, maternal and new-born deaths, maternal morbidity and chronic conditions (Glasier *et al.*, 2006). Family planning services also strengthen economies by reducing the pressure on limited health and natural resources in developing countries (Singh *et al.*, 2003; Groce et al, 2009).

For persons with disabilities, access to sexual and reproductive health services not only ensures attainment of their sexual and reproductive health rights, but also protects them from sexually transmitted infections including HIV and AIDS, all of which are very important due to their increased vulnerability to sexual exploitation and abuse (Groce et al, 2009; Lee *et al.*, 2015). According to Groce et al (2009), persons with disabilities are three times more likely to be victims of physical and sexual abuse than persons without disabilities. As a result, they are at risk of sexually transmitted infections. Women with disabilities also benefit from reproductive health services because the services reduce their susceptibility to childbirth complications, which may lead to maternal morbidity and further disabilities (Glasier *et al.*, 2006; Mavuso and Maharaj, 2015). Nonetheless, when accessing sexual and reproductive health services both women and men with disabilities encounter a number of challenges, including socio-cultural norms, service provider's negative attitudes and structural challenges such as high maternity beds (Smith *et al.*, 2004; WHO and UNFPA, 2009; Ahumuza *et al.*, 2014). Even though persons with disabilities experience challenges in accessing SRH services, few studies report on how these challenges are influenced by the impairments or health conditions of persons with disabilities (Yousafzai *et al.*, 2004; WHO and UNFPA, 2009; Mavuso and Maharaj, 2015).

Research on persons with disabilities has shown that decreased mobility, manual dexterity, sensory deficits and epilepsy all negatively affect the utilization of sexual and reproductive health services among women with disabilities (Nosek *et al.*, 1995; Becker, Stuifbergen and Tinkle, 1997; Welner, 1999; Nosek *et al.*, 2001). For example, Nosek et al (2001) in their study of women with

physical disabilities found that 11% of women with disabilities were less likely to use condoms compared to 17% of women without physical disabilities because of limited manual dexterity. Servais et al (2002) also found that only 18.5% of women with intellectual disability in Belgium used oral contraceptives compared to 46% of the general population due to their epilepsy medication which reduces the effectiveness of the contraceptives. Although there is available information on the link between disability and contraceptive use, few studies in the sub-Saharan African region have been conducted to examine this link, due to limited information on the proportion of persons with disabilities (Loeb and Eide, 2004; De Beaudrap *et al.*, 2016; ACFA, 2017). Most researchers have concentrated on understanding contextual factors (environmental and social) that hinder persons with disabilities from accessing SRH services. Therefore, the following paragraphs discusses the environmental and social challenges that persons with disabilities in sub-Saharan Africa experience when accessing sexual and reproductive health services.

2.5.2   Challenges in accessing sexual and reproductive health services among persons with disabilities in sub-Saharan Africa

2.5.2.1   Limited access to Sexual and reproductive health information

Among the many challenges that persons with disabilities face in accessing sexual and reproductive health services is limited access to sexual and reproductive health information (Smith *et al.*, 2004; Kassa *et al.*, 2016). Persons with disabilities have limited access to information because of lack of communication about sexual and reproductive health issues between persons with disabilities and their family members (Wazakili, Mpofu and Devlieger, 2006; Mavuso and Maharaj, 2015). Lack of sexual and reproductive health information in alternative formats such as braille or large print, or lack of sign language interpreters in health facilities, also contribute to the challenges faced by persons with disabilities (Ahumuza *et al.*, 2014; Mavuso and Maharaj, 2015). Societal beliefs that they are sexually inactive and that they do not therefore require sexual and reproductive health information, have also been found to contribute to the challenges faced by persons with disabilities, when accessing SRH services (Rusinga, 2012; Mprah, 2013; Kassa *et al.*, 2016).

In South Africa, Swaziland and Cameroon, persons with disabilities have poor knowledge of sexual and reproductive information, such as HIV and AIDS, because of poor communication with their immediate family members (Yousafzai *et al.*, 2004; Wazakili, Mpofu and Devlieger, 2006; Bremer, Cockburn and Ruth, 2010; Mavuso and Maharaj, 2015). According to Mavuso et al (2015) and Wazakili et al (2006) there is limited communication between persons with disabilities and their

family members on sexual and reproductive health in South Africa, because these family members perceive persons with disabilities as children who do not have sexual feelings. Thus, they consider that persons with disabilities do not need to know about sexual and reproductive health issues. Such lack of communication leads to marginalisation and exclusion of persons with disabilities (Mavuso and Maharaj, 2015). Lack of communication also puts persons with disabilities at risk of being sexually abused, and increases the likelihood that they will not report incidences of abuse, due to fear of not being trusted (Wazakili, Mpofu and Devlieger, 2006; Mavuso and Maharaj, 2015).

Low literacy levels and employment status of persons with disabilities also compound their vulnerability and exclusion from SRH information and prevention and treatment services. In Sub-Saharan Africa, the literacy level for adults with disabilities is estimated to be at 3% and for women with disabilities to be at 1% (Groce and Bakhshi, 2009). The low literacy of persons with disabilities creates difficulties in communicating information about HIV and AIDS and other sexual and reproductive health issues. For example, in Ethiopia, only 65% of young persons with disabilities are aware of sexual and reproductive health services because of their lack of education (Kassa *et al.*, 2016). This lack of education exposes them to the risk of sexually transmitted infection including HIV and AIDS. Nevertheless, there are other formats of communicating sexual and reproductive health information to persons with disabilities such as drama and songs, however, Mprah (2013) and Mavuso et al (2015) have reported that persons with visual and hearing impairment experience difficulties in accessing information through such modes of communication. The findings from Mprah (2013) and Mavuso et al (2015) studies, demonstrate that there is a need for taking into account the specific needs of persons with different types of impairments, when developing ways to provide information on sexual and reproductive health.

2.5.2.2   Experience at health facilities

 Many persons with disabilities experience physical and attitudinal barriers when accessing sexual and reproductive health information and services at health facilities (Bremer, Cockburn and Ruth, 2010; Tanabe *et al.*, 2015). The physical challenges range from lack of ramps (which makes it difficult to manoeuvre for those in wheelchairs) , high maternity beds, inaccessible consultation rooms and elevators that are often out of services (Bremer, Cockburn and Ruth, 2010; Ahumuza *et al.*, 2014; Mavuso and Maharaj, 2015; Tanabe *et al.*, 2015). According to Bremer et al (2010), inaccessible consultation rooms in some health facilities in Cameroon create difficulties for women with physical disabilities, to the extent that some women have to be carried in order to enter a doctor's office. Studies have reported that such experiences make women with physical

disabilities feel ashamed, so that they shy away from visiting health facilities (Bremer, Cockburn and Ruth, 2010). Nonetheless, these researchers and some others do not clearly explain how such facilities affect the sexual and reproductive health needs of persons with mental or intellectual disabilities whose physical needs may be different from those with physical impairments.

In addition to physical challenges, persons with disabilities also face attitudinal barriers from both health service providers and their fellow clients (Smith *et al.*, 2004; Mavuso and Maharaj, 2015). Health services providers have a negative attitude towards the sexual health of persons with disabilities because of the misconception that persons with disabilities are asexual beings, who do not require reproductive health services (Smith *et al.*, 2004). In Zambia, health service providers do not expect women with physical disabilities to be pregnant or to seek family planning methods because of the asexual belief. Therefore when a pregnant physically impaired woman visits the health facility for prenatal care, the service providers advise the women to terminate the pregnancy (Smith *et al.*, 2004). For those seeking family planning methods they are not given any family planning choices, they are just advised to sterilise (Smith *et al.*, 2004). These attitudinal behaviours discourage both men and women with disabilities from accessing sexual and reproductive health services because they feel that health service providers are not willing to address their needs (Ahumuza *et al.*, 2014; Mavuso and Maharaj, 2015).

2.5.2.3   Societal attitudes towards persons with disabilities

The general perception and treatment of persons with disabilities in the sub-Saharan Africa region also influence persons with disabilities access to sexual and reproductive health services. Disability in some parts of the region like Ghana and Malawi is perceived to be as a result of a curse, punishment for sins committed by persons with disabilities or their family members or the result of witchcraft, magic or sorcery (Munthali, Mvula and Ali, 2004; Kwadwo, Anafi and Sekyere, 2014). These cultural belief creates stigma and discrimination towards persons with disabilities, such that they are denied access to employment or skills that can improve their well-being, to such an extent that they end up being street beggars (Munthali, Mvula and Ali, 2004; Kwadwo, Anafi and Sekyere, 2014). This social stigma and discrimination towards persons with disabilities leads policy makers in disability and sexual and reproductive health policies, to ignore the sexual and reproductive health needs of persons with disabilities (Kwadwo, Anafi and Sekyere, 2014). The omission of SRH needs of persons with disabilities in national policies is a problem, because policies are the basis for programmes on health services provision and the training of health service providers.

Some traditional beliefs also expose persons with disabilities to the high risk of sexually transmitted infections including HIV and AIDS (Munthali, 2011; Ahumuza *et al.*, 2014; Mavuso and Maharaj, 2015). For example, in some parts of Malawi, there is a belief that if an HIV positive person without a disability has sexual intercourse with a person with disability, the person gets cured (Mji et al 2008; Munthali, 2011). In South Africa and Uganda, women with disabilities are also believed to be sexually inactive or asexual beings, who are less likely to indulge in sexual relationships (Ahumuza *et al.*, 2014; Mavuso and Maharaj, 2015). These misconceptions subject women with disabilities to sexual exploitation, which in-turn increases their risk of sexually transmitted infections including HIV. Thus, there is a need for addressing the misconceptions that people have towards the sexual health of persons with disabilities, so that persons with disabilities can be protected from sexually transmitted infections.

To address the physical, attitudinal and socio-cultural challenges that persons with disabilities are facing in the region, researchers have proposed that there should be an extensive training of health service providers, to improve their attitude towards persons with disabilities (Smith *et al.*, 2004; Bremer, Cockburn and Ruth, 2010; Ahumuza *et al.*, 2014; Mavuso and Maharaj, 2015; Tanabe *et al.*, 2015). The researchers have also proposed that the service providers should also be equipped with the necessary skills for addressing the sexual and reproductive health needs of persons with disabilities (Smith *et al.*, 2004; Bremer, Cockburn and Ruth, 2010). Researchers have also proposed the creation of awareness on the sexual and reproductive health needs of persons with disabilities, through budgeting for disability inclusion in outreach programs and the engagement of persons with disabilities in the development of policies and programmes (Munthali, Mvula and Ali, 2004; Ahumuza *et al.*, 2014; Mavuso and Maharaj, 2015; Tanabe *et al.*, 2015).

This study proposes an investigation of the conceptual understanding of disability among the community members and an examination of the factors that guide in the development of disability inclusive programmes. The conceptual understanding of disability should be investigated to determine the disability issues that need to be prioritised when developing disability awareness campaigns. An exploration of the factors that guide in the development of disability inclusive policies and programmes is also important because policies are the basis for the development of sexual and reproductive health service provision programmes. The conceptual understanding of disability was investigated through focus group discussions and evaluations of the self-reported disabilities that were collected during the MWHS-2003. Regarding policies and programmes on sexual and reproductive health service provision, the study used key-informant

interviews with policy makers or programme managers and a desk review of the available policies in Malawi.

2.6 Frameworks for analysing factors influencing access to sexual and reproductive health services among persons with disabilities

This study reviews the Human Rights Based Approach that uses principles of the Convention on the Rights of Persons with Disabilities (CRPD) to examine how access to sexual and reproductive health services among persons with disabilities is analysed. Disability is a human rights issue because it affects the well-being of persons with disabilities. Persons with disabilities experience inequalities particularly when they are denied access to health care due to their disabilities (WHO and UNFPA, 2009; WHO and World Bank Group, 2011; Mavuso and Maharaj, 2015). Their autonomy is also violated especially when they are subjected to involuntary sterilization or advised to abort their pregnancies (WHO and World Bank Group, 2011; Tanabe *et al.*, 2015). Therefore, failure to recognize their right to access sexual and reproductive health services can result in further marginalisation and poor health.

The study also reviews the WHO's International Classification of Functioning Disability and Health (ICF) framework, because it provides a comprehensive description of the multidimensional aspect of disability including biological, psychological, social and environmental aspects (World Health Organization, 2002; Kostanjsek, 2011). It also identifies different kinds and levels of disability which provide the foundations for country-level disability data to inform policy development (World Health Organization, 2002).

The following section discusses the two frameworks, particularly how they conceptualise disability, analyse persons with disabilities' access to sexual and reproductive health services, their applications and limitation. The conceptualization of disability in the two frameworks will be discussed in order to decide which disabilities this study will focus on. A discussion on how the frameworks analyse persons with disabilities' access to sexual and reproductive health services provides a basis for the proposed factors in the current study's conceptual framework.

2.6.1 Human Rights Based Approach conceptual framework

One of the frameworks that has been used to analyse factors that influence access to sexual and reproductive health services among persons with disabilities, is the Human Rights Based Approach (HRBA). The HRBA is grounded on the principles of the Convention on the Rights of Persons with Disabilities (CRPD). Vaughan et al (2015) in their "Women with Disability taking Action on

Reproductive and sexual health (W-DARE)" project in the Philippines, used the principles of CRPD to analyse factors that influence women with disabilities' access to sexual and reproductive health services. The HRBA is summarised in figure 2.6:1;

Box 2.6:1 **Human Rights Conceptual Framework**

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1. Respect for inherent dignity, individual autonomy including the freedom to make one' own choice and the independence of persons.
2. Non-discrimination
3. Full and effective participation and inclusion in society
4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
5. Equality of opportunity
6. Accessibility
7. Equality between men and women
8. Respect for the evolving capacities of children with disabilities and respect for children with disabilities to preserve their identities

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Principles that underlie the CRPD (Njelesani *et al.*, 2012)

The Human Rights Based Approach (HRBA) is a conceptual framework which was developed by the United Nations for the process of human development and is normatively based on International human rights standards and operationally directed to promoting and protecting human rights (UNHRBA, 2017).

> The HRBA focuses on the inherent dignity of the human being and if necessary on the person's medical characteristics. It places the individual at centre stage in all decisions affecting him or her and locates the main problem of disability outside the person and in society. The problem of disability under this framework emanates from a lack of responsiveness by the state and civil society. It is thus the state's responsibility to tackle socially created obstacles in order to ensure full respect for the dignity and equal rights of all persons (Degener, 2014 ,p.16).

According to the HRBA framework, persons with disabilities fail to access sexual and reproductive health services because they are not involved in decision-making concerning family planning methods (WHO and UNFPA, 2009; WHO and World Bank Group, 2011; Njelesani *et al.*, 2012). Thus, they lack the autonomy to choose the methods that suit their sexual and reproductive

health needs. Persons with disabilities also fail to access SRH services because of discriminatory attitudes of the programme implementers who fail to recognize the diversity of persons with disabilities, particularly the gender dimension (Njelesani *et al.*, 2012). Exclusion of persons with disabilities from social participation also hinders them from raising issues concerning their needs and holding decision-makers accountable (Katsui, 2008; Njelesani *et al.*, 2012). The HRBA framework further proposes that persons with disabilities fail to access SRH services because of inaccessible transport, communication and information in both urban and rural areas.

This human rights-based approach is universally applied especially in low to middle-income countries like Malawi and the Philippines, because it ensures that persons with disabilities are incorporated into the mainstream of development (Katsui, 2008; Vaughan *et al.*, 2015). It puts persons with disabilities in the limelight; this means that disability has to be tackled at all levels. However, disability is a complex phenomenon whose nature and severity depend on the socio-cultural context of the population under study (Mont, 2007a; Loeb, Eide and Mont, 2008). This complex nature of disability creates difficulties in understanding what disability is and in identifying persons with disabilities (Katsui, 2008). For example, in societies where persons with visible impairments are discriminated against because of cultural or traditional beliefs, persons with mild or invisible impairments may not be discriminated against by the general public but they may not be included in disability benefits schemes because they are not identified as persons with disabilities (Holzer, Vreede and Weigt, 1999). This classification of disability makes the operationalization of the human rights-based approach difficult in some areas, including Sub-Saharan Africa, because of differences in the understanding of disability.

The other benefit of using a human rights-based approach is that it leaves the obligation of securing the human rights of persons with disabilities in the hands of the state. Persons with disabilities become the right-bearers and the state becomes the primary duty-bearer (Katsui, 2008). This country-centred approach is relevant in the context of disability because it is the states that sign and ratify International conventions or enact national legislations, thereby making promises for their citizens (Katsui, 2008). However, prioritization of disability issues in policies or programmes in most sub-Saharan African countries is difficult because of limited information on persons with disabilities. This situation is because of the socially created shame of family members who do not register household members with disabilities on any official documents (Katsui, 2008; Tanabe *et al.*, 2015). Information on persons with disabilities is also limited because of the approaches used in estimating the number of persons with disabilities. According to the 2011 World report on disability, most sub-Saharan African countries measure disability using a direct question of "does name has a disability". This approach produces low estimates as it focuses on severe cases of disability (WHO and World Bank Group, 2011 ,p.21-25). Therefore,

even though the policy makers may want to fulfil their state obligation of addressing the sexual and reproductive health needs of persons with disabilities, they may fail to do so due to the limited information on persons with disabilities.

2.6.2   International Classification of Functioning, Disability and Health (ICF) framework

The other model that has been used to investigate access to sexual and reproductive health services among persons with disabilities is the International Classification of Functioning, Disability and Health (ICF) framework. Smith et al (2004), in their study of women with physical disabilities in Zambia, used the ICF conceptual framework drawn in figure 2.6:1 to examine factors that influence women with physical disabilities access to reproductive health services. The ICF framework is a conceptual framework developed by the World Health Organization and adopted by the general assembly in 2001 (World Health Organization, 2001). The overall aim of the ICF framework is to provide a common language and a framework for understanding disability (World Health Organization, 2001;2002; Jette, 2006). It also provides a basis for identifying different levels of disability which provides the foundation for country-level disability data to inform policy and development (World Health Organization, 2002). In the ICF framework, disability is conceptualised as an outcome of a complex relationship between an individual's health condition, personal factors and external factors of the environment in which she or he lives.

The ICF framework considers the health of a person in two ways; through functioning and disability and through contextual factors as depicted in figure 2.6:1. Functioning and disability of the ICF framework encompass a description of body functions and structures, activities and participation (Jette, 2006; Meyer *et al.*, 2016). Body functions include psychological functions whilst body structures include organs and limbs. Activities refer to the execution of a task or an action by an individual whilst participation relates to an individual's involvement in a life situation. The health of a person in the ICF framework may be negatively impacted through an impairment (e.g. loss of sight), activity limitation (e.g. mobility difficulties) and participation restriction (e.g. difficulties in forming relationships) (World Health Organization, 2001;2002; Meyer *et al.*, 2016). The second part of the ICF framework corresponds to contextual factors that consider the impact of environmental factors (such as attitudes of health professionals, organizational policies and family or friends) and personal factors (including age and gender) on a person's functioning.

The advantage of using the ICF framework to study access to sexual and reproductive health services among persons with disabilities is that it provides a common platform for classifying disability, which is useful for comparing disability data within and across nations (World Health

Organization, 2001;2002; Jette, 2006). However, the framework raises difficult questions about the basis for the classification (Holzer, Vreede and Weigt, 1999; Jette, 2006; Whiteneck, 2006). It also raises questions about persons involved in producing the classification and the social-cultural context of populations under study (Jette, 2006). In the context of sexual and reproductive health services, these questions need to be clarified because they have implications for the classification outcome and on policy development and implementation. For example, in communities where the main economic activity is farming or fishing, individuals with mobility impairments may be at a disadvantage compared to those with hearing loss because those with hearing loss can manage to farm and fish (Holzer, Vreede and Weigt, 1999). This means that certain types of impairments may be considered as being more disabling compared to others, depending on context.

The other advantage of using the ICF framework in sexual and reproductive health studies is that it acknowledges the role of contextual factors particularly personal and environmental factors on functioning and disability (World Health Organization, 2002; Whiteneck, 2006; Masala and Petretto, 2008). Studies that have researched the link between environmental factors and persons with disabilities' participation in societal activities have shown that there is a complex relationship between environmental barriers and a person's participation in societal activities (Whiteneck *et al.*, 2004; Whiteneck, Gerhart and Cusick, 2004). For example, Whiteneck et al (2004) found environmental factors such as transportation, need for help in the home, availability of health care and government policies to account for only 4 percent of the variation in participation among persons with spinal cord injury, but 10 percent on quality of life (Whiteneck *et al.*, 2004; Whiteneck, 2006). This study finding supports the inclusion of environmental factors in the ICF framework but raises the question of whether or not environmental factors, such as the attitude of community members, directly influence the participation of persons with disabilities and of whether or not persons with disabilities are able to overcome these environmental barriers.

Figure 2.6:1 International Classification of Functioning, Disability and Health (ICF) framework

Health Condition

(Disorder or disease)

Body Functions & Structure ⟷ Activity ⟷ Participation

Environmental Factors

Personal Factors

Contextual Factors
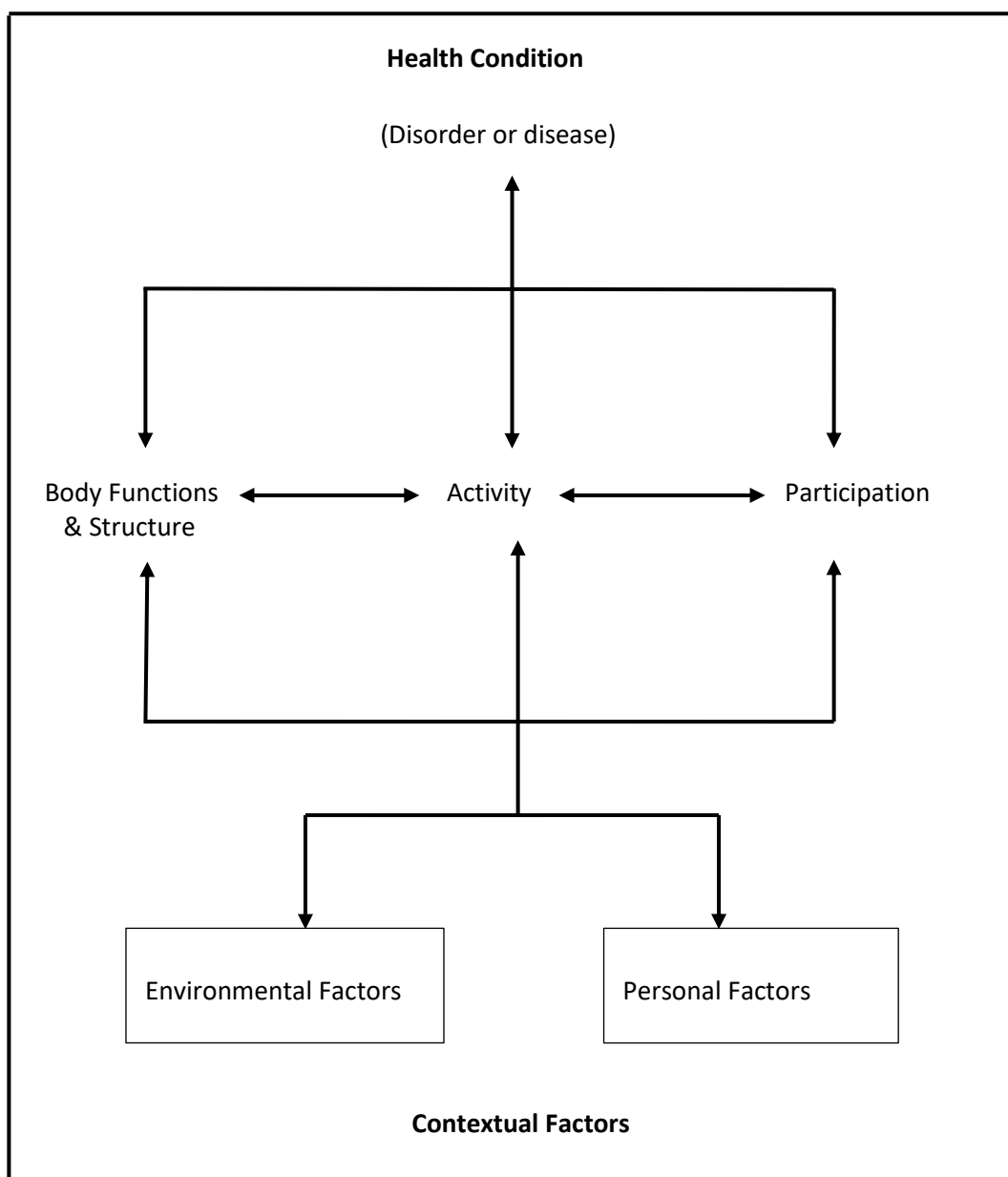
Source: (World Health Organization, 2002)

2.7 Proposed conceptual framework for analysing access to sexual and reproductive health services among persons with disabilities in Malawi

An examination of the HRBA and the ICF framework in sections 2.6.1 and 2.6.2 has demonstrated that the complex nature of disability creates difficulties in understanding disability and identifying persons with disabilities. The difficulty in identifying persons with disability then leads to the limited prioritization of disability issues in policies and programmes. The discussion on the ICF framework has also demonstrated that even though the ICF framework provides a common language or understanding for identifying persons with disabilities, there still remains issues with the classification of different types of disabilities because of socio-cultural context of various populations. Nonetheless, comparing the ICF framework and the HRBA, the ICF framework is an ideal model for studying access to sexual and reproductive health services among persons with disabilities. This is because its conceptualization of disability incorporates the multifaceted nature of disability. The ICF framework also incorporates the role of environmental and personal factors in the disablement process.   Therefore, this study utilizes the ICF framework drawn in figure 2.7:1 to examine the link between disability measurement and uptake of sexual and reproductive health services in Malawi.

The ICF framework drawn in figure 2.7:1, conceptualises disability as dysfunctioning in one of the three interlinked levels- impairments in body function or structures, activity limitation or participation restrictions. This conceptualization translates to the measurement of disability as an impairment or as functional limitation (activity limitation and participation restriction). This study, therefore, hypothesizes that utilization of sexual and reproductive health services among persons with disabilities is influenced by their physical or psychosocial impairments (intellectual or mental health problems). This hypothesis is drawn from studies that have investigated the sexual and reproductive health behaviour of persons with disabilities (Nosek, Wuermser and Walter, 1998; Servais *et al.*, 2002; Long-Bellil *et al.*, 2017) . For example, Long-Bellil et al (2017) in their study of the impact of physical disability on pregnancy and childbirth in the United States, found physical disabilities or impairments such as Spinal Cord Injury , Osteogenesis imperfecta and spinal muscular atrophy to affect the women's pregnancy and childbirth. For instance, during child birth a woman with a Spinal Cord Injury was more likely to have an epidural during her childbirth to prevent autonomic dysreflexia, compared to a woman who had no Spinal Cord Injury (Long-Bellil *et al.*, 2017). Servais et al (2002) in their study of contraceptive use among women with Intellectual disability in Belgium, also found intellectual impairment or disability to affect the use of contraceptive methods. The study found women with mild to severe intellectual disabilities to

likely use female sterilization compared to oral contraceptive methods than women without intellectual disabilities (Servais *et al.*, 2002). Women with intellectual disabilities were using female sterilization because of their non- compliance to contraceptive methods and their vulnerability to sexual assault.

The other disability measures that the study hypothesises to influence the uptake of sexual and reproductive health services among persons with disabilities is the functional limitation measure (activity limitation and participation restriction). Research on access to sexual and reproductive health services among persons with disabilities has indicated that activity limitation and participation restriction influences persons with disabilities access and utilization of sexual and reproductive health services. For example, Wu et al (2017) in their study of use of reversible contraceptive methods among women with physical or sensory disabilities, found experience of difficulties in walking, climbing, dressing or bathing to be negatively associated with the use of Intrauterine devices (IUDs) and progestin implants. In Cameroon, persons with mobility difficulties were also found to report difficulties associated with physical accessibilities of sexual and reproductive health services compared to those with no difficulties (DeBeaudrap *et al.*, 2019). In addition to physical accessibility, study participants with hearing difficulties also reported higher levels of communication difficulties when access sexual and reproductive health services such as HIV testing services compared to those with no hearing difficulties. These study findings demonstrate that there is a link between functional measures of disability and uptake of sexual and reproductive health services.

Apart from conceptualizing disability as dysfunctioning in one of the three interlinked levels, the ICF framework drawn in figure 2.7:1, also indicates that disability is a result of the negative interaction between a health condition and contextual factors that includes environmental and personal factors. With regards to access and utilization of sexual and reproductive health services among persons with disabilities, this study hypothesizes that personal factors such as age, gender, culture and empowerment and autonomy influences access and utilization of sexual reproductive health services among persons with disabilities. With regards to age, Mosher et al (2017) found age of the woman to significantly affect utilization of family planning services among women with disabilities. For example, among women aged 15 to 24, Mosher et al (2017) found that there were no significant differences in receipt of family planning services between women living with disabilities and those without disabilities. However, among women aged 25 to 44, women living with disabilities were less likely to receive family planning services compared to women without disabilities. With regards to empowerment, Smith etal (2004) in their study of

physical impaired women in Zambia, found low self-esteem among women with physical disabilities, to contribute to the women's low uptake of pregnancy and childbirth services.

Apart from personal factors, the perception of parents of persons with disabilities and persons with disabilities themselves, may also contribute to the limited access of sexual and reproductive health services among persons with disabilities. Literature on the sexual and reproductive health of persons with disabilities, has indicated that well-meaning parents of children with disabilities may discourage their children from accessing SRH services such as contraceptive methods, for fear that it may lead to ridicule by other family members and community members (Di Giulio, 2003; Wazakili, Mpofu and Devlieger, 2006). For example, in South Africa, Wazakili et al (2006) found that young women with disabilities were failing to access HIV and AIDS services because of the over protection of their parents. The parents were over-protecting the young women with disabilities by treating them as children who are unable to take care of themselves. In addition to parental perception, the perception of vulnerability to sexual and reproductive health problems by persons with disabilities themselves also contributes to their utilization of sexual and reproductive health services. For example, in Nagaland and Manipur states of India, a high proportion of persons with disabilities were not aware that family sexual abuse was a potential transmission route of HIV for persons with disabilities (Morrow *et al.*, 2007). The low knowledge was as a result of their perception that they were not at risk of acquiring the HIV virus.

Further to the influence of parental perceptions, literature also indicates that the policy environment of a population also contributes to the limited utilization of sexual and reproductive health services among persons with disability. According to Hanass-Hancock et al (2011), there is limited utilization of sexual and reproductive health services particularly HIV services among persons with disabilities in Eastern and Southern Africa because less than 50% of national strategic plans of the countries in this region recognise disability as an issue of concern. Persons with disabilities are not recognised as being at increased risk of acquiring the HIV virus (Hanass-Hancock, Strode and Grant, 2011). In the few countries where disability is perceived as an issue there is limitation information on how the sexual and reproductive health services should be provided to persons with disabilities. The non-inclusion of disability issues in policies and programmes has also be observed by Abdul Karimu (2018) in Ghana. Abdul Karimu (2018) observed that the 2016 Ghanaian adolescent health policy had no information on adolescent with disabilities. The policy did not also provide specific indicators for addressing the sexual and reproductive health needs of adolescents with disabilities(Abdul Karimu, 2018). The non-availability of specific indicators and information on persons with disabilities led to the development of policy interventions that fail to address existing inequities in the provision of health services. This study therefore proposes that the non-inclusion of disability issues in policies

and programmes influences the utilization of sexual and reproductive health services among persons with disabilities.

Figure 2.7:1 Conceptual Framework for analysing access to Sexual and Reproductive Health Services among persons with disabilities

Health Condition → Pre-existing condition. Or condition acquired due to contextual factors e.g. HIV or Tuberculosis

(Disorder or disease)

Physical impairments
Psychosocial impairments ← Body Functions and Structures ↔ Activity ↔ Participation → **Restricted participation in** Sexual and reproductive health education programmes / Sexual and reproductive health information / Formulation of policies and programmes on sexual and reproductive health

Difficulties in
Mobility
Self-care
Communication
Domestic life

Environmental Factors   Personal Factors →

Age, gender
Personal and social values
Income and social capital
Caregiver support
Empowerment and autonomy

Physical influences
Distance to health facilities
Inaccessible minibuses
Physical environment e.g. lack of ramps, bed height, doorways
Lack of mobility assistive devices
Inaccessible roads and bridges

Social and Attitudinal Influences
Traditional beliefs
Social norms
Ignorance/lack of knowledge about disability
Expectations of poor care and bad attitudes
Fear of bad reception, complications and caesarean section
Attitude of others
Poverty

Policy or institutional influences
Professional values and norms
Technical and interpersonal quality
Stakeholder needs and perceptions
Availability of disability data or information
Transparency
Lack of screening equipment

Modified ICF framework (World Health Organization, 2002)

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2.8   Conclusion of literature review

In conclusion, this chapter has presented an overview of the conceptual understanding of disability, its measurement, data limitations and other issues that relate to persons with disabilities' access to sexual and reproductive health services. It has highlighted the concept of disability from a medical model perspective to a biopsychosocial model, where disability is perceived as an interaction between health conditions and an individual's personal and environmental factors. Issues surrounding disability measurement and data limitations have also been discussed. Chapter three will present how issues of disability measurement and data limitations have been addressed in this thesis

3 Chapter 3: Research design, type and sources of data used in the study

3.1 Overview

This chapter discusses the research design, sources of data used in the analysis, and their quality. Section 3.1 is an outline of the chapter, section 3.2 gives a review of the main research designs, which provides a basis for the choice of research design used in this study. This chosen design is then discussed. Section 3.3 describes the sources of data used and their quality.

3.2 The research design for the study

Bryman (2016) and Creswell (2017) explain that there are three main research designs that provide a framework for collecting and analysing data in social sciences. The research designs include quantitative, qualitative and mixed methods. The quantitative research design is a research strategy that focuses on the collection and analysis of numerical data (Bryman, 2016). This research design also examines the relationship between variables. The variables can be measured using questionnaires in population polls, surveys or experiments and analysed using statistical, mathematical or numerical procedures (Bryman, 2016; Creswell and Creswell, 2017). Researchers who use quantitative research designs, deductively test hypothesises or theories, aim to protect against bias, control for alternative explanations and generalise their research findings to the entire population or sub-population groups (Creswell and Creswell, 2017).

A qualitative research design, on the other hand, is a strategy for collecting and analysing data that focuses on understanding the meaning of a phenomenon within a particular context without referring to any other causation (Edmonds and Kennedy, 2012; Bryman, 2016; Creswell and Creswell, 2017). When collecting and analysing data using qualitative research designs, researchers aim to explore the "how" and "why" of systems and human behaviours (Edmonds and Kennedy, 2012). Qualitative researchers also tend to collect data in the field, or at the site where the participants experience the problem or the phenomena (Creswell and Creswell, 2017). In qualitative research designs, researchers can use multiple approaches within a single study to collect data. A researcher can observe the behaviour of individuals in a community, can use focus group discussions, key informant interviews or in-depth interviews (Bryman, 2016; Creswell and Creswell, 2017). The collected information is then analysed using both inductive and deductive

techniques. Inductively, a researcher builds patterns, categories and themes from the collected data, which is from the bottom to the top. Deductively, "a researcher looks back at the data from the themes to determine if more evidence can be gathered to support each theme", (Creswell and Creswell, 2017).

Even though qualitative research designs provide a broad overview of a phenomenon and the researcher is fully involved in the collection of the data, this research design has limitations. According to Atieno et al (2009), the results obtained from qualitative research designs cannot be generalised to the entire population with the same degree of certainty as those obtained from quantitative research designs. Barbour (2000) also reports that it is difficult to investigate causality between different research phenomena. The difficulty in investigation arises due to the difference in quality and quantity of information obtained from different participants (Barbour, 2000). To address the problems encountered due to the use of qualitative methods, researchers resort to the use of quantitative methods whose results are generalizable. However, there are also limitations associated with the use of quantitative methods. According to Rahman (2017) quantitative research does not "account for how social reality is shaped and maintained, or how people interpret their actions and those of others". The other limitation of a quantitative research is that it only provides a snapshot of the phenomenon understudy (Rahman, 2017). That is to say the measured variables only explain the phenomenon at a specific moment in time and disregards whether the photograph happened to catch one looking one's best or looking unusually disarranged (Rahman, 2017). Therefore to ensure that the phenomenon understudy provides a social reality and that it is generalizable to the entire population, researchers use a mixed-method research design.

A mixed method research design is a research strategy that involves combining or integrating quantitative and qualitative research designs within a single project (Bryman, 2016; Creswell and Creswell, 2017). The purpose of conducting a mixed method research design is to expand and strengthen the study findings. For example, Campbell and Fiske (1959) employed a mixed method research design to demonstrate that the results obtained from their study were not due to the research method that they had used, but were due to the phenomenon under study. When using a mixed method research design, quantitative and qualitative methods within a project can be combined either sequentially or concurrently (Creswell and Creswell, 2017). In a sequential mixed method design, a researcher may employ quantitative approaches in the first phase of the study and in the second phase employ qualitative approaches of data collection and analysis. In a concurrent mixed method research design, "the researcher collects quantitative and qualitative data at the same time and compares the databases to determine convergence ", (Creswell and Creswell, 2017). Even though a researcher has the opportunity to combine the two research

designs sequentially or concurrently, they may still face some difficulties in using mixed methods research designs, because they need to learn the multiple approaches and how to mix them appropriately (Johnson and Onwuegbuzie, 2004).

The current study has adopted a mixed method research design. A mixed method research design has been adopted through the guidance of the conceptual framework. The conceptual framework hypothesizes that the limited utilization of sexual and reproductive health services among persons with disabilities in Malawi, is a result of the approaches used in estimating the number of persons with disabilities and the perceptions that policy makers and community members have towards disability. Examining the perceptions or conceptual understanding of disability requires an exploratory study and the assessment of approaches used in estimating the number of persons with disabilities requires quantification, hence the adoption of a mixed method design. Since a conceptual framework is guiding the choice of a research design, a sequential transformative strategy of combining the quantitative and qualitative methods has been adopted to address the objectives of the study (Creswell and Creswell, 2017). The sequential transformative strategy gives the qualitative and quantitative methods the same weight. This means that neither of the research methods is superior to the other.

3.3   Type and sources of data used to assess the self-reporting of disability in Malawi (in Chapter 4)

To address the second part of the first research objective, i.e., examining the influence of people's perception of health states on self-reported measurement of disability, the study uses the 2003 Malawi World Health Survey (MWHS-2003) dataset. The MWHS-2003 dataset is used in this study because it allows one to examine people's perception of health states through the use of anchoring vignettes. The MWHS-2003 is also the only nationally representative dataset that is comparable across countries (Witvliet, 2014).

The data for the 2003 Malawi World Health survey was collected with the intent of evaluating the performance of health systems and of monitoring inequalities in health status and health financing (Szwarcwald and Viacava, 2005). The survey was developed and conducted by the World Health Organization (WHO). The survey collected the health information using two questionnaires (household and individual questionnaire). The household and individual questionnaires collected information on the health of individuals in the households. The health information included general health, daily functioning, chronic conditions and mental health (World Health Organization, 2003; Witvliet, 2014). The two questionnaires were also used to collect information on health-care usage, health-care costs, and the household and personal

socio-economic situation. In addition to the two questionnaires, the survey also used anchoring vignettes and cards to evaluate people's perceptions of various health states. When collecting information using anchoring vignettes (or hypothetical stories) and the cards, participants were divided into four groups. For anchoring vignettes, each group of participants were requested to evaluate 10 health state conditions on a functioning scale of 1 to 5. Where 1 represented no difficulty, 2=mild, 3=moderate, 4=severe and 5 represented extreme difficulty in functioning. With regards to the cards, each set of participants were asked to rank five health states from the worst health condition to the least serious. The questionnaires were translated into Chichewa and adapted to the Malawian situation, particularly in relation to income indicators. The survey used face-to-face interviews to collect information from the respondents.

Selection of households in the MWHS-2003 was achieved through use of a random stratified sampling procedure. The sampling procedure involved dividing the country into three regions, i.e., North, Central and South. The regions were further divided into urban and rural areas. It was from the urban and rural areas of the various regions that 5,490 households were selected. The MWHS-2003 targeted individuals aged 18 years and older. In the 5,490 selected households; 5504 individuals were selected for an interview but only 5, 297 were interviewed. Of the 5,297 individuals that were interviewed, 2,584 were male and 2,713 were female.

3.3.1   Quality checks on the data used to assess the measurement of disability in Malawi

The quality of data from a population survey is affected by two types of errors namely; sampling and non-sampling errors. Sampling errors are errors that occur in the dataset because a sample of the population was used in carrying out a survey, instead of the entire population (Murthy, 1967; Üstun *et al.*, 2005). According to Üstun et al (2005), the quality of survey data is affected by the sample size, the variability of the sample estimate from population quantities and the sampling technique used in the survey. Non-sampling errors in surveys on the other hand, may arise due to the ambiguity of the concepts used in the questionnaire, the method of interview, incomplete coverage of the population sample and the coding, or tabulation of the data (Murthy, 1967; Üstun *et al.*, 2005).

To ensure that the MWHS-2003 dataset is of good quality, a number of quality assurance measures were undertaken before and after the survey. The WHO team, pilot-tested the survey instruments in three countries; the United Republic of Tanzania, the Philippines and Colombia (WHO and World Bank Group, 2011). In addition to pilot testing, the instruments were also used in the WHO Multicounty survey study that was conducted in 61 countries, where 14 surveys were carried out using face-to-face interviews. The disability instruments were also translated into

several languages including Chichewa to further refine them and make them culturally adaptable. Immediately after translation and before the commencement of the World Health survey, the survey instruments were further tested in China, Myanmar, Pakistan, Sri Lanka, Turkey and the United Arab Emirates (WHO and World Bank Group, 2011).

Even though the disability instruments were thoroughly tested before the survey for cultural adaptability, an assessment of the instruments in Brazil during the WHS-2002 survey indicates that the instruments were not compatible with the Brazilian cultural context. For example, when people were asked to evaluate their health in-terms of feeling sadness or depression in the last 30 days. The survey participants reported that they have a low mood and made additional comments like …" *but it's not surprising because I've been out of work…times are hard, right?*" (Azevedo, Queiroz and Rezende, 2005). This comment indicates that the low mood was not due to any chronic health condition but due to their current socio-economic status. This illustrates that the phrasing of the questions in the instruments was not compatible with the Brazilian context. With regards to the Malawian context, pain and discomfort are the norm in the farming community, the questions on pain and discomfort could have been misreported because of the failure of the participants to differentiate normal health and ill health. Nevertheless, the questions in the various domains focused as far as they could on the intrinsic capacities of an individual in a particular domain (WHO and World Bank Group, 2011).

Apart from pilot testing the survey instruments, the survey selected the households of the survey participants using a random, stratified sampling procedure and selected the participants using Kish tables. These strategies provide a known non-zero probability of selecting a household and an individual (World Health Organization, 2003; Üstun *et al.*, 2005). The known non-zero selection probability procedure improves the quality of the data by allowing extrapolation of the data to the entire population (World Health Organization, 2003).

In addition to sampling, the quality of the data was also improved with the use of Geographic Information Systems (GIS). GIS refers to any information associated with a location on the Earth's Surface (World Health Organization, 2003). Research on non-sampling errors has indicated that data from population surveys may be affected by curb side or fictitious interviews (de Lepper, Scholten and Stern, 1995; Üstun *et al.*, 2005). Fictitious interviews are interviews where interviewers or research assistants just sit alongside the road or under a tree and fill out the survey questionnaire themselves (Üstun *et al.*, 2005). To ensure that the MWHS-2003 has not been affected by curbside interviews, the MWHS-2003 researchers used GIS to verify that the fieldwork has been executed.

Apart from the use of GIS, the quality of the data was also improved through the use of statistical techniques. The statistical techniques used included Sampling deviation index (SDI), test-retest reliability and degree of non-response and missing data. A sampling deviation index (SDI) " is a measure of the degree to which the sample deviates in representativeness from the target population", (Üstun *et al.*, 2005). Mathematically, the SDI is written as,

$$SDI = \sum_{a=1}^{a} |1 - index_a| \qquad (3.1)$$

(Üstun *et al.*, 2005)

Where:
- a=age categories
- Index = is the ratio of the sample in the age category to the population in the age category from the United Nations (UN) population database or other updated sources such as the country's Census.

The index shows the extent to which the sample represents the population in terms of age or sex distribution. The Homogeneity of the index can be tested using a Chi-square test or the pi-star test. An index or ratio value of 1 indicates that the age or sex category of the sample survey is truly representative of the general population.

The data collected from the 2003 Malawi World Health survey, was also examined using the sampling deviation index. Figure 3.3:1 presents the representativeness of the MWHS-2003. The figure demonstrates that age categories 18 to 19; 20 to 24; 25 to29; 30 to 34; 40 to 44; 60 to 64 were truly represented the general population, because their index values were close to 1. For age categories 35 to 39; 45 to 49; and 55 to 59, their index values were slightly lower than the expected value of 1. This indicates that the populations in these age categories were under-sampled. The figure further demonstrates that populations in the age categories 50 to 54; 70 to 74; 75 to 79; 80 to 84 and 85 to 89 were over-sampled, as shown by their index values of above 1. Nevertheless, a pi-star significant test of the sample indicates that the overall survey sample was a true representation of the target population with a pi-star of 0.28.

Figure 3.3:1 Sample Deviation index for Malawi
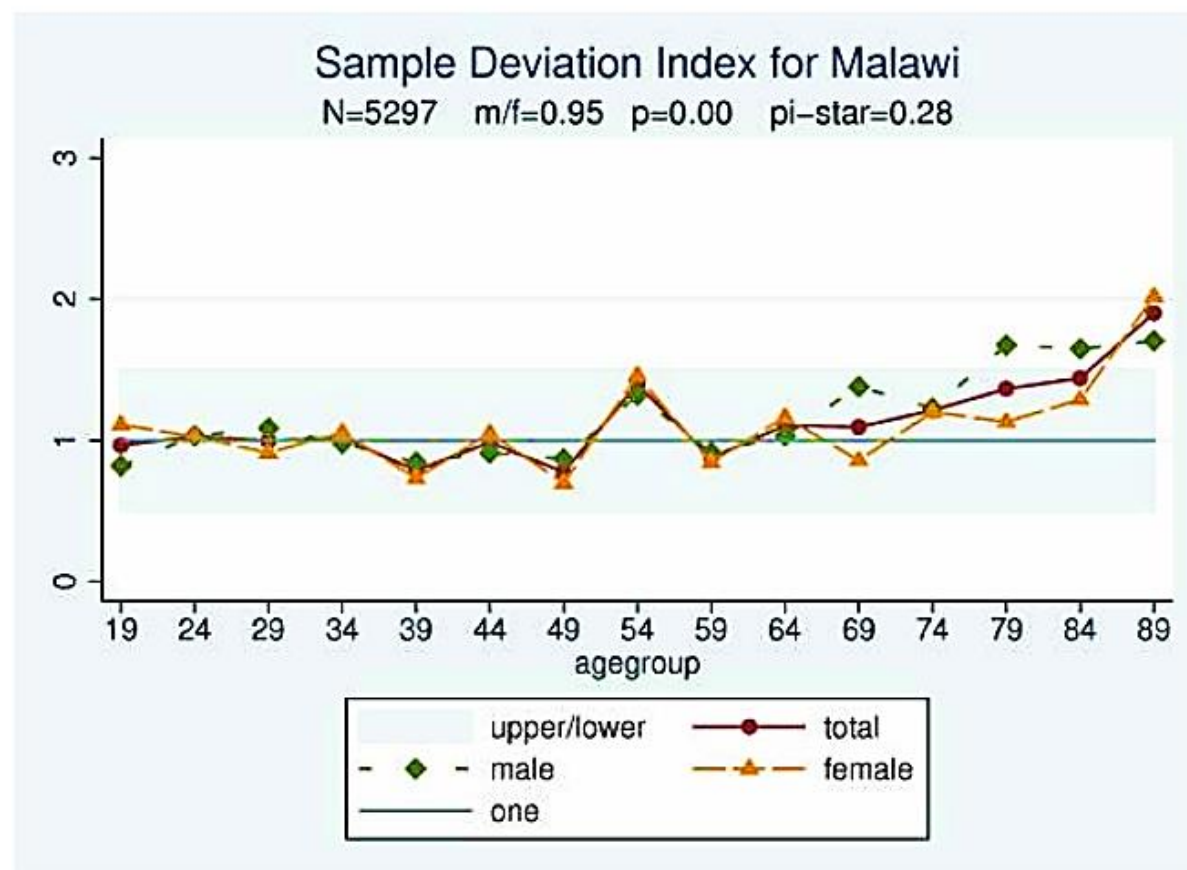
Source: Adapted from the MWHS-2003report

With regards to the completeness of the survey, the survey was assessed in-terms of non-response and missing data. Non-response in this survey referred to " the number of completed interviews among persons or households eligible for inclusion (a selected "household" that turns out to be a vacant dwelling was not eligible for inclusion)", (Üstun *et al.*, 2005). The non-response indicator was used to demonstrate the performance of the survey with respect to the aim of achieving a 100 per cent response rate. For the WHO World Health Survey, the minimum response rate was set at 75%. In Malawi, 5,880 households were selected for inclusion into the survey, but only 5,490 households were interviewed. With regards to survey respondents, 5,504 participants were selected for inclusion in the survey but only 5,297 were interviewed, representing a response rate of 96%. Comparing the household and individual response rates of Malawi to the WHO minimum response rate of 75%, the results from Malawi indicate that the completion rate of the 2003 Malawi World Health survey was well above the minimum.

 In terms of missing data, the MWHS-2003 report indicates that mortality (deaths to children and adults) and coverage, (experience of health problems and health care) information was not completely covered in the survey with a missing rate of 9% for each factor. The WHO had set a

minimum acceptable range of 10% for face-to-face interviews, therefore a 9% missing rate for mortality and coverage was not a bad outcome for the Malawian survey. Moreover, in Malawi it is unusual for a family to obtain a death certificate when a relative dies, so most of the people could just have been recalling (NSO, 2005).

In summary, procedures for assessing the quality of the data were conducted both before and after the survey. The research instruments were pilot tested in three countries and used in a Multicounty survey before the worldwide World Health survey. Before the commencement of the survey, the instruments were also translated and pilot-tested again to ensure that the translated instruments were collecting the right information. After the collection of the data, the datasets were also statistically analysed to assess for completeness, missing data and representativeness. In Malawi, the analytical results indicate that the data is a true representation of the target population. The survey had an above minimum completion rate and the missing information on mortality and coverage was within the acceptable range of 10% (Üstun *et al.*, 2005). To further examine the quality of the MWHS-2003, the following section discusses the reliability of the survey instrument in measuring disability.

3.3.2   Reliability of the survey instrument in measuring disability in Malawi

Disability in the 2003 Malawi World Health survey was measured in two ways; as an impairment and in relation to functional limitation. The impairment component was measured through an observation. The research assistants for the survey were asked to observe their participants during the data collection and to record any physical or mental impairments that their participant had. The functional limitation component on the other hand, was measured in line with the World Health Organization International Classification of Functioning, Disability and Health (ICF) framework. The ICF framework hypothesizes that disability results from a "negative interaction between persons with an impairment and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others" (World Health Organization, 2002; Hendricks, 2007; WHO and World Bank Group, 2011). Disability in this ICF framework therefore involves dysfunctioning in the domains of body functions and structures including activity and participation (World Health Organization, 2002; Salomon *et al.*, 2003). Table 3.3.2 below summarises the ICF framework components and domains.

Box 3.3:1 ICF components and domains

Body function:	Activities and participation:
Mental functions	Learning and applying knowledge
Sensory functions and pain	General task and demands
Voice(s) and speech functions	Communication
Functions of the cardiovascular, haematological, immunological and respiratory systems	Mobility
	Self-care
Functions of the digestive, metabolic, endocrine systems	Domestic life
Genitourinary and reproductive functions	Interpersonal interactions and relationships
Neuromusculoskeletal and movement-related functions	Major life areas
Functions of the skin and related structure	Community, social and civic life
Body structure:	**Environmental factors:**
Structure of the nervous system	Products and technology
The eye, ear and related structures	Natural environment and human-made changes to environment
Structures of the cardiovascular, immunological and respiratory systems	Support and relationships
Structures related to the digestive, metabolic and endocrine systems	Attitudes
	Services, systems and policies
Structures related to genitourinary and reproductive systems	
Structures related to movement	
Skin and related structures	

Source: (World Health Organization, 2002 , p.16)

For the MWHS-2003 survey, functional limitation was measured based on eight health domains, namely, mobility, self-care, pain and discomfort, cognition, interpersonal activities, vision, sleep and energy, and affect (Salomon *et al.*, 2003; WHO and World Bank Group, 2011). According to Salomon et al (2003), the eight health domains were used as a measure of disability because they are the core domains of health that are considered important in societal health goals and are generally accepted as capturing the content of the ordinary meaning of health. The eight health domains were also selected for cross-population comparability (WHO and World Bank Group, 2011). However, in Malawi, the main disabling conditions at the time of the survey were HIV and AIDS, Lower respiratory infections and diarrheal diseases (Bowie, 2006). Therefore, the eight health domains were not the best measures of disability or health, because apart from causing mobility problems, pain and discomfort, HIV and AIDS, Lower respiratory infections and diarrheal, affect a person's breathing patterns, skin and disfigurement and social functioning. Thus, the eight health domains excluded participants with breathing, skin and disfigurement and social functioning problems.

During the MWHS-2003 survey, participants were asked about difficulties over the last 30 days in functioning in eight health domains. The survey instrument asked the participants about their difficulty in functioning over the past 30 days, instead of the duration of their functioning difficulties, because it intended "to provide a cross-sectional snapshot of functioning among the participants in different country surveys that could be aggregated to the population level", (WHO and World Bank Group, 2011). The responses to each health domain were on a 5 point scale ranging from no difficulty (a score of 1) to extreme difficulty or cannot do (a score of 5). The 2003 Malawi World Health Survey was an International survey. This means that the questions used to measure disability were similar or identical to the ones that were asked in all other countries such as Brazil.

This study therefore, examines the questions relating to the eight health domains to judge their reliability in measuring disability or functional limitation in Malawi. The reliability test was conducted using a Cronbach's alpha test. Cronbach's alpha test has been chosen in this study, to examine the error factors that may have occurred due to the use of a range of items for measuring disability. In other words, the study intends to measure the internal consistency in estimating disability using the range of items. Cronbach's alpha is thus a right measure in this study because "it takes into account the variance that is attributable to subjects and the variance that is attributable to the interactions between subjects and the items", (Cortina, 1993).

Cronbach's alpha is based on the assumption that each test item measures the same latent trait on the same scale (Tavakol and Dennick, 2011). Therefore, if a factor analysis of the items indicates that there are multiple factors or traits that are being measured by the items; the assumption of the same latent trait is violated. Cronbach's alpha can be mathematically defined as

$$\alpha = \left(\frac{k}{k-1}\right)\left(1 - \frac{\sum_{i=1}^{k} \sigma_{y_i}^2}{\sigma_x^2}\right)$$ (3.2)

(Tavakol and Dennick, 2011)

Where:

- k= the number of scale items
- $\sigma_{y_i}^2$ = the variance associated with item $\dot{\iota}$
- σ_x^2 = The variance associated with the observed total score

In providing the overall assessment of a measure of reliability, the resulting α coefficient of reliability ranges from 0 to 1. If all the items in the scale are independent of one another (meaning that they are not correlated or share no covariance) the value of α if close to 0 (Goforth, 2015).

When the items in the scale measure the same trait or when they are correlated or share covariance, the value of α is close to 1. A Cronbach's alpha of between 0.70 and 0.90 is perceived as a better estimate of reliability. A Cronbach's alpha of less than 0.70 is an indication of a low number of questions, poor inter-relatedness between items or heterogeneous constructs (Tavakol and Dennick, 2011). When the value of Cronbach's alpha is too high, it may suggest that some of the items in the scale are redundant, or they are testing the same questions but in a different way.

Table 3.3:2 presents the results obtained from assessing the reliability of the questions used in measuring disability in the MWHS-2003. The table has eight columns. The Health domain column presents the eight health domains that were used to measure the level of functioning difficulty or disability in the survey. The eight health domains are, as mentioned before, mobility, self-care, pain and discomfort, cognition, interpersonal activities, vision, sleep and energy and affect. The observation column indicates the number of non-missing observations for each item. The sign column indicates the direction in which an item entered the scale. A positive sign indicates that the item was entered in its observed format; a negative sign indicates that the item was reversed. In this study, all the disability measurement items were entered as observed.

The item-test correlation column shows how each item is correlated with the overall scale. The results in table 3.3:2 indicate that, most of the items have a correlation coefficient of above 0.5 except the vision item on ''seeing an object at arm's length''. This vision item needs to be removed from the scale because it is not correlated to the overall scale. However, removing this item would not significantly change the overall scale, as shown by its alpha value in the alpha column. Therefore, it was not removed in this study.

Next to the item-test correlation column is the item-rest correlation column. The item-rest correlation column shows how each item is correlated with a scale computed from only the other 15 items. The results in the item-rest correlation column indicate that the items, ''dealing with conflict'', ''seeing a person across the road'' and ''seeing an object at arm's length'' are poorly correlated with a scale computed from the rest of the items. The three items have a correlation coefficient of less than 0.5. To improve the measurement scale, these three items were supposed to be removed from the measurement scale, however, an investigation of their alpha coefficient in the last column of the table indicates that removing any of these three items could not have significantly improved the reliability of the scale. Therefore the three items were not removed from the measurement scale.

The other column in the table is the average inter-item covariance column, which is a measure of how much on average, the items vary from each other. The results in the table indicate that on

average the items have a variation coefficient of 0.383. The variation coefficient demonstrates that there is minimal variation between the items.

The last but one column is the alpha column, which can be interpreted as "the squared correlation between the score a person obtains on a particular scale (the observed score) and the score he or she would have obtained if questioned on all possible items in the universe (the true score)", (Marija, 2003). The output of this column indicates how the alpha scale would change if the item was deleted from the scale. For example, if the vision item "seeing an object at arm's length'' were removed from the scale, what would be the overall alpha scale? The results in table 3.3:2 in the alpha column indicates that, if the ''seeing an object at an arm's length'' item was removed then the alpha scale would be (α=0.910). This alpha coefficient is not very different from the overall alpha scale of (α=0.909), that is why the item was not removed. The table further indicates that the overall alpha coefficient of the disability measurement scale is (α= 0.909), which is slightly above the acceptable value of 0.90. This alpha value then is acceptable because it is not too far from the acceptable range. This therefore indicates that the eight health domains were measuring a unidimensional disability trait in the Malawian population.

To sum up, this section aimed to assess the reliability of the eight health domains in measuring disability in Malawi. The assessment was accomplished through the use of Cronbach's alpha test. The results from the Cronbach's alpha test indicate that the example question on difficulty in ''seeing an object at arm's length'' was not a good measure of disability. However, the item was not removed because its removal would not significantly improve the overall measurement scale. The domain questions, difficulty in dealing with conflict and seeing a person across a road also had a low correlation coefficient with a scale computed from the rest of the items. Just like the question on difficulty ''seeing an object at arm's length'', the items, ''dealing with conflict'' and ''seeing a person across the road'' were not removed because their removal would not improve the measurement scale as shown by their alpha coefficients. Nevertheless, the overall alpha scale (α= 0.909) is above the minimum of 0.70, which indicates that the eight health domains were a reliable measure of disability in Malawi. This means that the eight health domain questions can be used to assess the measurement of disability in Malawi.

Table 3.3:1 Reliability test of each item of the eight health domains

Health Domain	Obs.	Sign	Item-test Correlations	Item-rest Correlations	Average inter-item Covariance	alpha	Item label
Mobility							
q2010	5290	+	0.714	0.662	0.377	0.901	difficulty moving around
q2011	5287	+	0.731	0.680	0.375	0.900	vigorous activities
Self-care							
q2020	5289	+	0.716	0.664	0.377	0.901	Self-care
q2021	5285	+	0.711	0.658	0.377	0.901	maintaining general appearance
Pain & Discomfort							
q2030	5291	+	0.735	0.686	0.375	0.900	body aches or pains
q2031	5292	+	0.745	0.696	0.374	0.900	bodily discomfort
Cognition							
q2050	5293	+	0.658	0.597	0.383	0.903	concentrating
q2051	5174	+	0.637	0.574	0.385	0.904	learning a new task
Interpersonal relationships							
q2060	5280	+	0.618	0.552	0.387	0.904	personal relationship
q2061	5276	+	0.554	0.482	0.393	0.907	dealing with conflict
Vision							
q2071	5281	+	0.532	0.457	0.395	0.907	seeing a person across the road
q2072	5284	+	0.471	0.391	0.401	0.910	seeing an object at arm's length
Sleep and Energy							
q2080	5284	+	0.636	0.573	0.385	0.904	falling asleep
q2081	5279	+	0.668	0.609	0.382	0.903	feeling rested
Affect							
q2090	5282	+	0.634	0.571	0.385	0.904	feeling sad
q2091	5283	+	0.636	0.573	0.385	0.904	worry or anxiety
Test Scale					**0.383**	**0.909**	**Standardized items**

Note: q20* indicates the number of the question in the MWHS-2003 Individual questionnaire

3.4 Type and sources of data used to examine the uptake of SRH services in Malawi (in chapters 6 and 7)

To address the third research objective which focuses on examining the relationship between impairment and functional measures of disability and utilization of SRH services, this study used two datasets, the 2003 Malawi World Health Survey and the 2004 Malawi Demographic and Health Survey (MDHS-2004). This study combined the MWHS-2003 and the MDHS-2004 because

the MWHS-2003 had not collected information on access to and utilization of family planning services, such as injectable and intrauterine devices. The MDHS-2004 was also used in this study because it was conducted at a period that was close to the MWHS-2003. By using the MDHS-2004, it was assumed that the characteristics of the MDHS-2004 sample were similar to that of the MWHS-2003 sample, since they were collected from the same population.

The Malawi Demographic and Health Survey is a routine health survey that is conducted every five years to assess fertility and mortality trends in the country. For the MDHS-2004, the purpose was to provide an up-to-date database on family planning and fertility behaviour of the population, so that policymakers can evaluate and enhance family planning initiatives in the country. The survey was also designed to "examine basic indicators of maternal and child health and welfare in Malawi, including nutritional status, use of antenatal and maternity services, treatment of recent episodes of childhood illnesses and use of immunisation services", (NSO, 2005). Unlike the MDHS-2000, the MDHS-2004 also collected blood samples to estimate the prevalence of HIV in the country.

The data for the MDHS-2004 was collected from 13,664 households that were selected through cluster sampling. Before the commencement of the survey, 522 clusters were drawn from the 1998 population and housing census sample frame. Among the 522 clusters, 458 were from rural areas and 64 were from urban areas. Having drawn the clusters from the census sample frame, the Malawi National Statistics Office staff conducted a listing of all the households in each cluster. The household list was then used to draw a systematic sample of 15,091 households. In the selected households, 12,229 women aged between 15 and 49 were eligible for individual interview, but only 11,698 were interviewed. With regards to male participants, males aged 15 to 54 were selected from every third household of those households selected for an interview. A total of 3,797 male participants were eligible for an interview but only 3,261 were interviewed. In addition to sampling, the survey also used Global Positioning System (GPS) devices to establish and record geographic coordinates of each household in the selected clusters (NSO, 2005).

To collect information on fertility behaviour and maternal and childhood health, the survey used three types of questionnaires; household, women and men questionnaires. These questionnaires were adapted from the MEASURE DHS model questionnaires. The Household Questionnaire was used to collect basic information from all usual members of the households and the visitors. The basic information included age, sex, education and relationship to the head. The women's questionnaire was used to collect information on reproduction, knowledge and use of family planning methods, maternal and child health, fertility preferences, HIV and domestic violence. The men's questionnaire collected information that was similar to that of the women but

excluded reproductive history, maternal and child health, adult and maternal mortality (NSO, 2005). The reproductive history was not collected from the male respondent because of the demographic understanding that it is the reproductive history of women that contribute to population growth (Rutstein and Rojas, 2006).

3.4.1 Quality checks on data used to examine the uptake of SRH services in Malawi

To ensure that MDHS-2004 data was of good quality, the Malawi National Statistical Office staffs, employed cluster and systematic sampling to select participants to the survey. Cluster sampling improves the quality of the data by reducing the variability of the results observed from the survey (Henderson and Sundaresan, 1982). Systematic sampling, on the other hand, ensures that the population is evenly sampled. These sampling techniques also eliminate the clustering of survey participants which often occurs when using simple random sampling (Madow, 1949). To produce district level estimates that are reliable, the following districts; Mulanje, Thyolo, Kasungu, Salima, Machinga, Zomba, Mangochi, Mzimba, Blantyre and Lilongwe, were oversampled (NSO, 2005).

In addition to sampling, the quality of the data from the MDHS-2004 was also improved through the pre-testing of the survey questionnaires. The three questionnaires (household, women's and men's) were pre-tested in all three regions of the country: North, Central and South. The observations made during the pre-testing fieldwork and suggestions made by the pre-testing field teams, were then used to revise the skip patterns, wording, and translation of the questionnaires (NSO, 2005).

Apart from pre-testing of the questionnaires, the quality of the data was also assessed through data entry. When entering the data into the computer, the quality of that data was verified through double entry (two individuals entering the same data). The double entry exercise was done with the assistance of a software package called CSPro. The CSPro software enabled the Malawi National statistics Office team, to not only double check the quality of the data, but also enabled them to edit the inconsistencies that were found by the computer program. Overall, the response rate of the survey was 97.8% for the household, 95.7% for women and 85.9% for men (NSO, 2005).

3.5 Type and sources of data used to explore the conceptual understanding of disability in Malawi (in chapter5)

To address the research questions on how disability is conceptualized in Malawi, the study used qualitative research methods of data collection and analysis. There are various qualitative and quantitative methods for examining people's conceptual understanding of disability. Quantitatively, people's conceptual understanding of disability can be examined using health assessment questionnaires such as the Washington Group short set of questions and health-state preference measures such as Time-Trade-off (TTO). Qualitatively, the conceptual understanding of disability can be explored using focus group discussions and in-depth interviews. The following paragraphs discusses some quantitative and qualitative methods that can be used to examine people's understanding of disability.

Quantitatively, people's conceptual understanding of disability may be examined using self-health assessment measures, such as the Washington Groups short set of questions, where participants are asked to rate their health state in various domains of health such as dressing. The Washington Group short set of questions, asks participants to rate their health state (in eight health domains: vision, hearing, mobility, communication, cognition, self-care, upper body and affect (Washington Group on Disability Statistics (WG), 2008). The main advantage of using health assessment questionnaires, to understand people's conceptualization of disability is that they shed light on people's health concerns (McDowell, 2006). Health assessment questionnaires also provide an understanding of people's perception of good health and health-seeking behaviour. Nonetheless, health assessment measures have limitations. The main limitation is that the given responses are affected by the contextual background of the participant (Salomon, Tandon and Murray, 2004; Sabariego *et al.*, 2015).

Apart from using health assessment measures, people's conceptualizations of disability may also be examined using health state preference measures, such as Visual Analogue Scale (VAS), Standard Gamble (SG) and the Person Trade-off (PTO). When using health-state preference measures, participants are asked to evaluate various health states and to state their preference by either using a scale or trade-off (Froberg and Kane, 1989; Brazier, Deverill and Green, 1999). For example, when using the Time-Trade-off (TTO) participants are presented with two alternative health scenarios and are asked to choose their preferred health state. The participants may be asked to choose between living for the rest of their life in an impaired health state (e.g. living with tuberculosis) or living in full health for a short period of time (e.g. 2 years) (Whitehead and Ali, 2010). The advantage of using health-state preference measures, is that they assists in evaluating the health status of various population groups and the effectiveness of health

interventions (Froberg and Kane, 1989). Health state-preference measures also help in determining appropriate community services for the elderly. The main limitation of health-state preference measures is that, community members may have little or no experience of the health conditions in the given scenarios (Whitehead and Ali, 2010).

With regards to qualitative methods, people's conceptual understanding of disability can be explored using a focus group discussion, where a small group of people with similar backgrounds or experiences gather together to discuss a specific topic of interest (Wong, 2008; Overseas Development Institute, 2009). The participants of the group are guided by a moderator (or group facilitator) who introduces the topic of discussion and assists the participants to participate in a lively manner (Overseas Development Institute, 2009). A focus group discussion is an important method for exploring people's conceptual understanding of disability, because it allows the participants to agree or disagree with each other. These interactions provide insight into how the participants think about the issue under discussion and the variations that exist due to community beliefs, practices and experiences (Overseas Development Institute, 2009). Nonetheless, focus group discussions are subjected to bias, because the given information may be influenced by the dominant participant or the moderator (Wong, 2008).

The other qualitative method that can be used to explore people's conceptual understanding of disability is an in-depth interview. An in-depth interview involves conducting a direct one on one intensive interview with a small number of participants, to elicit a vivid picture of each participant's perspective on a particular idea or situation (Guion, Diehl and McDonald, 2001; Mack *et al.*, 2005; Boyce and Neale, 2006). For example, study participants may be asked about their perception, beliefs and attitude towards disability. During the in-depth interview, the study participant is regarded as the expert and the interviewer is considered as the student. The potential benefit in conducting an in-depth interview is that, it provides a relaxed environment which enables the participant to talk freely about their personal feelings, opinions and experiences (Mack *et al.*, 2005; Boyce and Neale, 2006). However, it is difficult to verify an individual's opinion or experience, thus the results may be biased towards the individual's opinion (Morris, 2015). The other problem of in-depth interviews is that the results are not generalizable, due to the smaller sample size and non-use of random sampling techniques (Boyce and Neale, 2006).

Given the quantitative and qualitative approaches that can be used to examine the understanding of disability among community members, this study used focus group discussions. Focus group discussions were used instead of in-depth interviews ,to provide an insight into the dynamics of cultural norms and the variations in people's experiences with disability (Kitzinger,

1995; O'Day and Killeen, 2002). This study also used focus group discussions instead of in-depth interviews to clarify the collected information through the participant's interactions.

3.5.1   Study setting

Between the 11th of October and the 13th of December 2017, information on community member's conceptual understanding of disability was collected from participants in Zomba and Blantyre districts of Malawi. The two districts were purposively sampled because of their ease of access and cost-effectiveness in terms of transport and accommodation.

Zomba district

Zomba district is situated in the southern part of Malawi and is surrounded by Chiradzulu, Blantyre, Mulanje, Phalombe, Machinga and the Republic of Mozambique to the east (Malawi Government, 2007). Zomba has a heterogeneous population composed of different ethnic groups, cultures and languages. The main ethnic tribes in Zomba are Mang'anja or Nyanja, Yao and Lomwe. Nyanja is the native language that is spoken by most of the inhabitants in the district (Malawi Government, 2007). For Chinamwali, the main ethnic group is Mang'anja and for Jali1 the main ethnic group is Lomwe. There is no dominant traditional or cultural belief among people of Zomba because of the various ethnic tribes, but in rare cases such as drought, people try to conduct some rituals such as dance performances (Malawi Government, 2007). People in Zomba belong to many religions, but the most prominent religion in the district is Christianity (79%), followed by Islam (19%) (NSO, 2008). In terms of impairments, a high proportion of persons with impairments (24%) in zomba have visual impairment. For Zomba city, the highest problem is mobility impairment with a proportion distribution of 26.4% (NSO, 2010a).

Blantyre district

Blantyre is the commercial city of Malawi and is situated in the southern region of the country, surrounded by Zomba, Chiradzulu, Thyolo, Chikwawa and Mwanza (Malawi Government, 2010). The predominant tribe in Blantyre are the Mang'anja and Yao which constitute 60 % of the population (Malawi Government, 2010). The remaining 40% is made up of tribes such as the Lomwe, Ngoni, Sena, Tumbuka, and Chewa. In terms of the selected areas, the ethnic tribe of Bangwe is Mang'anja and Ngoni is the ethnic tribe of Daniel Village. There are many religions in Blantyre, but the predominant religion is Christianity (90%), followed by Islam (8%) (NSO, 2008). With regards to impairment, visual and mobility impairment are the main disabling conditions for Blantyre, each contributing 26 % of the impairment in the district. With regards to Blantyre city, the main disabling condition is visual impairment accounting for 30 % (NSO, 2010a).

3.5.2   Selection of participants

The target population for the focus group discussions were men and women aged 18, and above who live in rural and urban areas of Zomba and Blantyre districts. This age group was purposively sampled because they are more likely to have encountered a person with disability or experienced a disabling condition. Participants in the focus group discussions were selected from Chinamwali (a semi-urban area in Zomba) and Jali1 (a rural village in Zomba). In Blantyre, research participants were selected from Bangwe (one of the townships in Blantyre) and Danielle village (a village in Machinjiri, one of the Traditional Authorities in Blantyre rural). In each area, two focus group discussions were conducted separately for each gender.

Identification of participants for the focus group discussions was conducted in two stages.   The first stage involved seeking permission from the village head in the rural areas or the ward administrator or area chief in the urban areas. The research team, which was comprised of the researcher and three research assistants (two males and one female) would approach the village headman and present a letter from the district commissioner or district assembly (see Appendix, A2), requesting permission to conduct the study in the village or community. The village headman through his assistants then alerted the community members of the planned visit.

 In the second stage, the team purposively sampled households starting from the centre of the village. In the selected households, a member of the research team asked the household head for demographic information (names, sex and age) of all the household members. The demographic information was then used to select household members who were eligible to participate in the study (members aged 18 and above). The selected household members were then asked, using the study information sheet attached in Appendix A3, if they were willing to participate in the study. When a participant agreed to participate in the study, she or he was asked to sign a consent form as proof of their acceptance and they were informed that the discussion would be recorded. In total 8 single sex focus group discussions (4 males and 4 females) were conducted, as summarised in figure 3.5:1;

Figure 3.5:1 Flow diagram showing how participants to FGD were identified

District, Village or Township, Focus Group Discussion (FGD)

District
Zomba   Blantyre

Village or Township
Chinamwali   Jali 1   Bangwe   Daniel village

FGD
M F   M F   M F   M F
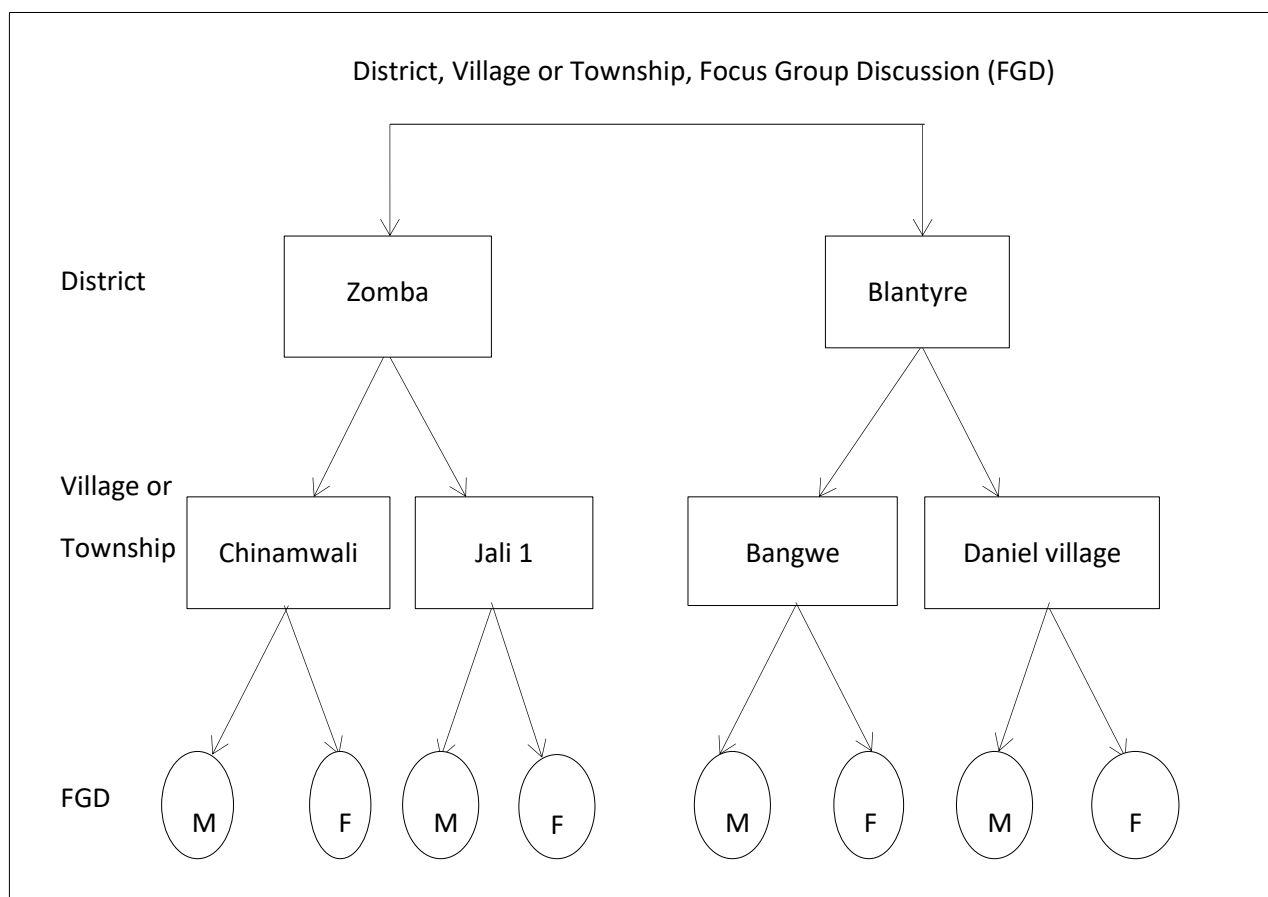
Source: Author's illustration of the study areas.

3.6 Type and sources of data used to examine the inclusion of disability issues in Malawi's SRH policies (in chapter 8)

To assess the inclusion of disability issues in Malawi's disability and SRH policies and programmes, the study evaluated health policy documents that are available in the country and conducted key-informant interviews with policy-makers and programme developers. A health policy in this study refers to "formal, written documents, rules, and guidelines that present policymakers' decisions about what actions are deemed legitimate and necessary to strengthen the health system and improve health", (Ivanova, Dræbel and Tellier, 2015). Policies in this case not only relate to the actual policy documents but also strategies, action plans or programmes.

Chapter 3

Health policies that have been evaluated in this study were collected from Malawi's Ministry of Health Website, United Nations Population Fund (UNFPA) Malawi website, Google, Google Scholar and PubMed. From these websites and search engines, nine policy documents were collected. The nine policy documents are: *National Health Policy*, *Malawi National Sexual and Reproductive Health and Rights strategy 2011-2016*, *Health Sector Strategic Plan II 2017-2022*, *National Sexual and Reproductive Health and Rights policy 2017-2022*, *National Cervical Cancer Control strategy 2016-2022*, *National Youth Friendly Health Services strategy 2015-2020*, *National HIV and AIDS policy 2011-2016*, *National Disability policy* draft, *2006 National Policy on Equalization of Opportunities for Persons with Disabilities*.

Key informant interviews were conducted with policymakers or policy formulators and programme developers in the Ministry of Gender, Children, Disability and Social welfare; Ministry of Health; Banja La Mtsogolo (BLM); Family planning Association of Malawi (FPAM); Malawi Human Rights Commission; Federation of Disability Organizations in Malawi (FEDOMA); Malawi Council for the Handicapped (MACOHA); Disabled Women in Development (DEWODE) and Christian Blind Mission (CBM). These government ministries, civil society organization and non-governmental organizations were targeted because they are the key players in the development and implementation of disability and SRH policies and programmes. Key informant interviews were conducted in Malawi from the 25th of September 2017 to the 15th of December 2017, following the approval of the University of Southampton Ethics and Research Governance Committee. Permission to conduct the study was also sought and received from the District Commissioners of Zomba, Blantyre and Lilongwe.

3.6.1 Selection of participants to Key informant interviews

Participants for the key informant interviews were identified with the assistance of social researchers working on disability and SRH at Chancellor College, a constituent college of the University of Malawi. When a participant had been identified, they were contacted by email or telephone. When a participant agreed to participate in the study, they were emailed a participant information sheet (attached in Appendix A6) to inform them of the study objectives and the information that they were expected to provide. Participants were also asked to choose a day when they would be available to be interviewed. On the day of the interview, participants were asked to sign a consent form (attached in Appendix A7) and were informed that the interview would be recorded. During the interview, participants were asked to explain about their understanding of disability, the factors that guide them in the development and implementation of disability or SRH policies and programmes, and the challenges they face when implementing disability inclusive SRH programmes. Overall, ten key informants from the sampled 9

organizations provided information on the inclusion of disability issues in Malawi's SRH policies and programmes.

3.7 Recruitment and training of research assistants for the qualitative survey

The researcher prepared an advertisement for research assistants. This advertisement was not only placed on the notice boards of Chancellor College, a constituent college of the University of Malawi but also on social media such as Facebook and WhatsApp. The researcher also consulted researchers in the research institutions in Zomba including the Centre for Social Research (CSR). The aim was to vet the applicants and shortlist only those who had interviewing and language communication skills, some knowledge of group dynamics and relevant research experience. Three research assistants (two males and one female) were recruited, based on the assessment of their curriculum vitae. All three-research assistants had college diplomas in different areas.

Prior to the fieldwork, the research assistants were trained. The training focused on the focus group discussions, key informant question guides, and interview techniques. The training also focused on the cultural beliefs and social expectation of the selected areas to bridge the power imbalance that might have risen due to the unfamiliarity of the study areas. The researcher also put an emphasis on the need to respect not only a participant's anonymity and confidentiality but also their right to withdraw from the study.

3.8 The role of the researcher: positionality and reflexivity

As the researcher has grown up in the country of research and works in one of the districts that was selected for fieldwork, her background might have introduced some personal and ethical dynamics to the research process during the fieldwork and the data processing time. Considerations of one's background, personal values and experiences during the research process have been found to be valuable when drawing conclusions and implications of the results of inquiry (Sultana, 2007; Holmes, 2014; D'silva *et al.*, 2016). The following sub-sections details how the researchers background and experiences could have influenced the research participants and the conclusions drawn from the focus group discussions and key informant interviews.

3.8.1 Positionality

Holmes (2014) describe positionality as a "reflection of the position that the researcher has adopted within a given research study which is normally identified by locating the researcher in

relation to the subject, the participants and the research context and process". Positionality may be perceived in terms of race, age, nationality, level of education, privileges and experience (Holmes, 2014). Reflecting on one's position in the research process is vital because it affects the research outcomes and interpretations, since the position of the person within the social world influences the way they view it (D'silva *et al.*, 2016). Positionality is also a positive and integral element of qualitative research because it defines the boundaries within which the research was produced (Jafar, 2018).

The doctoral researcher did her Bachelor's degree at Chancellor College, a constituent college of the University of Malawi in Zomba. She has also been working as a demography lecture in the department of population studies at this institution since 2009. The time that she spent studying and working in Zomba, has made her to be familiar with the cultural-traditions of people in Zomba. This familiarity with the cultural traditions of Zomba might have possibly influenced her interactions with the research participants in Chinamwali and Jali1 areas, because of her inside position. As an insider, it meant that she could easily be accepted by the focus group participants , but it also meant that the research participants could easily recognise the social fissures that distinguished them from the researcher (Ganga and Scott, 2006). Therefore, to minimise the bias that might have been introduced by the insider position of the researcher, the researcher asked the research assistants to moderate the focus group discussions whilst she focused on note taking.

Concerning the key-informant interviews, the researcher was one of the organizers of the 2014 African Network for Evidence-to-Action in Disability (AFriNEAD) conference. As an organizer, she closely worked with some disability organizations in the country including the department of disability, which is in the Ministry of Gender, Children, Disability and Social Welfare. By working with disability organizations, it meant that she developed some close working relationship with the people holding the management positions in these organizations. This meant that she could easily book for key informant interviews, but it also meant that her interviews would be affected by her familiarity with the key informants and the organization's activities. To minimise the bias that might have been introduced by the researcher's close working relationship with the key informants the researcher strictly followed the research guides during the interviews. The research guides are attached in Appendix A8- A11.

Apart from being an insider during the research process particularly the data gathering stage, a researcher can also be identified as an outsider (Ganga and Scott, 2006; Dwyer and Buckle, 2009; D'silva *et al.*, 2016). According to Fay (1996) cited in Dwyer et al (2009) being an outsider in the research process is beneficial because it helps the researcher "to appreciate the wider

perspective, with its connections, casual patterns and influences than one who is internal to the experience". Concerning the current study, in some of the focus group discussions, the researcher felt that she was an outsider and this helped her to conceptualise the experience of the community members. For instance at Daniel Village, the researcher had a focus group discussion with a group of women some of which had children with disabilities. The women who had children with disabilities discussed their perception of persons with disabilities accessing sexual and reproductive health services. In discussing the sexual and reproductive health of their children with disabilities, the doctoral researcher was able to understand the reason behind the women's perspectives. Thus as an outsider or as a person with child with no disabilities the researcher was able to understand why the women were for or against persons with disabilities utilizing sexual and reproductive health services.

3.8.2   Reflexivity

Apart from the position of the researcher introducing biases to the qualitative research, the involvement of the researchers in deciding what to investigate, who to sample, what questions to ask and which sections of the manuscripts to code and report might have introduced some biases (Creswell and Inquiry, 2007; Dwyer and Buckle, 2009). As noted by Creswell (2007) qualitative research cannot be separated from the researcher because it is shaped by the researcher's background and expectations. To reduce biases that arise from the decision to carry out an investigation and select the study participants, researchers have proposed the use of "reflexivity", (Plowman, 1995; Creswell and Inquiry, 2007; Mosselson, 2010). Reflexivity is "self-critical sympathetic introspection and self-conscious analytical scrutiny of the self as researcher", (Plowman, 1995). A critical analysis of a researcher's influence in the design, collection and interpretations of qualitative data is vital in qualitative research because it can lead to new insights and hypotheses about the research questions (Plowman, 1995; Dwyer and Buckle, 2009)

 With regards to this study, the need to understand how disability is conceptualised in Malawi and how issues of disability are incorporated in the country's policies and programmes led to the decision of conducting the qualitative research. Therefore when formulating the research instruments the researcher had to develop research questions that would be in line with the research objectives. However, this need for developing research questions that correspond to the research objectives might have introduced some biases to the qualitative research. The researcher could have developed questions that would direct the participants to provide responses that were in line with the research assistants. For example, instead of asking a general question like what is your understanding of disability, the researcher could have just written the disabilities that she is aware of and asked the participants to agree with her suggestions or to

provide their reasons for their disagreement. To minimise this bias, the researcher consulted her supervisors and an independent researcher during the development and collection of the qualitative data, to guide her in the formulation of the research questions.

3.9   Ethical considerations for the qualitative instruments

Before the commencement of the fieldwork, the research instruments were sent for review to the University of Southampton Ethics and Research Governance committee in the United Kingdom. Upon approval of the research instruments from the University of Southampton, permission to conduct the study in Zomba, Blantyre and Lilongwe districts was sought from Zomba, Blantyre and Lilongwe district assemblies. Prior to the focus group discussions participants were also read verbally the description and objective of the study. They were also informed about their voluntary participation, confidentiality and anonymity as well as their right to withdraw from the study without any repercussions. If a participant willingly agreed to participate in the study, they were asked to sign a consent form as proof for their consent. Those who could not sign were given inkpads so that they could sign with their thumbprint.

3.10 Challenges and fieldwork reflections

Collection of information on community member's conceptual understanding of disability through focus group discussions had minimal challenges. The research team had anticipated challenges in the recruitment of study participants because of the period at which the study was being conducted. This was a land preparation season for most farmers. To address this challenge the interviews were conducted in the afternoon after fieldwork. Nonetheless, challenges were encountered, particularly those relating to non-response, because some group participants were unwilling to provide their opinions, as a result, they just agreed with what their fellow group members were contributing. With regards to the key-informant interviews, the main challenge was on setting a date for the interview as most of the participants had busy schedules.

3.11 Generalisability of the study

The results of the qualitative component of this study cannot be assessed in a statistical sense because the key informants and the districts were not selected randomly. The demographic characteristics of the study participants can also not satisfy the demand for representativeness. However, the participants in the focus group discussions were from multiple ethnic tribes that permitted an understanding of multiple perspectives, attitudes and perceptions towards disability. Furthermore, a participant's classification of disabling conditions and their attitudes

towards persons with disabilities SRH behaviour provides a picture of what could have been obtained elsewhere, where the economic activity and literacy levels are the same as those of the study populations. With regards to key informant interviews, the purposively sampled informants are key in the development and implementation of disability and SRH policies and programmes.

3.12 Quality control measures for translation and transcription

To ensure that the information collected through focus group discussions and key informant interviews is consistent and reliable, a number of measures were undertaken during the preparation, data collection and analysis stages. Prior to fieldwork, both the key informant and focus group discussion guides were given to a peer researcher to evaluate the phrasing of the questions and their ability to collect information that would address the study objectives. The peer researchers noted that some of the questions could not be easily translated into the local language, so revisions were made to ensure that the local translation corresponded to the English version. The revised guides were then sent to two individuals for translations into the local language, Chichewa. The double translation was done to ensure consistency of the research instruments and their ability to collect the expected information. The translated instruments were then harmonised and reviewed again during the training of the research assistants.

During the data collection process, each focus group participant was given a number to use when responding to questions or providing their opinions to maintain anonymity. The research assistants also took note of each event before and after the discussion and while the discussion was in progress to ascertain that interruptions did not influence a participant's subsequent contributions, thus affecting the quality of the data. For example, at the beginning of the focus group discussion with men at Jali 1, all men were seated on the floor, but in the middle of the discussion, the village head, sent in some benches, so the men had to move from the ground to the benches. The change in sitting position from the floor to the benches did not interrupt any participant's contribution to the study.

With regard to transcription, research assistants were given time in between the data collection process to transcribe a recording of the focus group discussion or key informant interview. The researcher then read the transcription while listening to the interview to ensure that the recorded data was transcribed verbatim. This was done to check for consistency in transcription and translation and the quality of the collected information.

3.13 Data processing of focus group discussions and key informant interviews

Data management and analysis began during the data collection exercise and continued during the transcription. These preliminary stages enabled the researchers to have an overview of the issues that were emerging from the focus group discussions and key informant interviews. When all the recorded information was transcribed and translated from the local language to English, a Computer-Assisted Qualitative Data Analysis Software (CAQDAS) package, NVivo version 11.4 was used to manage and analyse the data. The Nvivo package was chosen instead of other qualitative data analysis software such as ATLAS.ti, MAXqda and N6, because it has features such as character-based coding, rich-text capabilities and multi-media functions that are relevant for qualitative data management (Zamawe, 2015). Nvivo is also a better data management software compared to other software, because it does not have a specific methodological design and analysis. It can work with discourse analysis, grounded theory, conversation analysis, ethnography, literature reviews, phenomenology and mixed methods (Richards, 2002; Zamawe, 2015).

In this study, Nvivo was used for coding, annotation and further interrogation of the collected data. Transcripts from the 8 focus group discussions and the 10 key informant interviews were entered into a folder in the sources file of the Nvivo package. The researcher then read each transcript to familiarise herself with the text, while making a brief note of the important issues that were emerging. This iterative process is vital in qualitative studies because it is key to the development of insight and meaning-making of the collected information (Srivastava and Hopwood, 2009). For example, when reading the transcript the researcher noted that some participants described disability in-terms of what they see (having a short leg) while others described it in terms of causes (having been sick for some time when you were a child then starting to experience difficulties when walking). These insights led the researcher to develop themes that were then collected in Nvivo as codes. In identifying the themes, a deductive approach was used whereby information from each transcript was then organised around the developed themes. An inductive approach was also used because some themes emerged during the coding process. The inductive approach permitted a better understanding of the issues relating to the conceptual understanding of disability, particularly when all the themes had been retrieved from the transcripts.

3.14 Conclusion

This chapter has discussed the research design, and the type and sources of data used to address the objectives of this study. In discussing the research design for the current study the chapter has described three main types of research designs that are used in social sciences. The chapter has also provided the reason for choosing a mixed method research design as a research design for this study. In addition to the research design, the chapter has also provided a description of the sources and quality of the data used to address the objectives of the study. The chapter has described the 2003 Malawi World Health survey and the 2004 Malawi Demographic and Health survey. In describing the quality of the MWHS-2003, the chapter has shown that the eight health domains that were used to measure disability or functional limitation in the survey are a reliable measure of disability in Malawi. The chapter has further discussed the qualitative techniques that were used to collect data for exploring the conceptual understanding of disability in Malawi. The qualitative techniques used were focus group discussions, a desk review and key informant interviews. The methods and techniques used to analyse both the quantitative and qualitative data have not been discussed in this chapter. The analysis will be discussed in each of the individual analytical chapters, because the objectives of this study are mutually exclusive, thus each study objective requires its own assumptions and analytical technique, hence the absence of any discussion of analytical techniques in this chapter.

4   Chapter 4: Assessing the self-reported measurement of disability in Malawi

4.1   Introduction

Disability is a complex phenomenon with no single definition or method of measurement. Its complexity arises from its reliance on the nature and severity of disability and the social, cultural context in which the research is being conducted (Grönvik, 2007; Mont, 2007a). In this study, disability refers to difficulty in performing socially and culturally acceptable daily activities due to health or physical problems (Verbrugge and Jette, 1994; World Health Organization, 2002). In population censuses and surveys, disability is frequently measured through self-reports or performance. Self-reported measurements assess the participant's perception of their performance difficulties, restrictions, or need for assistance associated with daily activities. Performance-based measures, measure the physical functioning of a participant by relying on a rater's assessment of a participant's performance of specific physical tasks, typically measured in controlled environments (Latham *et al.*, 2008). Functioning in this study refers to "an individual's ability to perform normal daily activities required to meet basic needs, fulfil usual roles and maintain health and well-being", (Leidy, 1994).

There have been debates about the relative advantage of using self-reported measures in relation to performance-based measures. This is because self-reported measures in theory have been found to be vulnerable to external influences such as cognition, culture, language and education (Fried *et al.*, 2000; Latham *et al.*, 2008; Jylhä, 2009). However, a number of studies that have compared self-reported measures to performance-based measures, have found self-reported measures to be more sensitive to functional changes in higher functioning populations   (Fried *et al.*, 2000) or to changes in specific-conditions such as low-back-pain (Fritz and Piva, 2003; Latham *et al.*, 2008). For example, in a study on mobility disability among older women in Baltimore, Maryland, U.S.A, Fried et al (2000) observed that women who had reported no mobility difficulty at the beginning of the 18-month study period, were found to have some mobility difficulties at the end of the 18 months. The decline in mobility among the women was measured using both self-reports and performance measures. The two measures provided evidence that indicated that the women had experienced a decline in mobility during the study period. Based on this evidence, researchers have recommended the use of both approaches in disability studies because they provide distinct but complementary information regarding functional status (Latham *et al.*, 2008).

Chapter 4

In the case of Malawi, self-reported measures of disability have been used in population censuses and surveys. However, the information collected, using the self-reported measures, is likely to have been affected by understandings of disability and the socio-economic characteristics of the sampled population. With regards to the understanding of disability, the available evidence indicates that there are some community members who report having no disability, but when they are asked about their functional status they report having some functional limitations (Loeb and Eide, 2004). This discrepancy in self-reporting indicates that there are issues in the conceptual understanding of disability.

Research on self-health assessments has also indicated that there are variations in the self-health assessment of disabling conditions or health status among young and old people (Idler and Benyamini, 1997; Miilunpalo *et al.*, 1997; Jylhä, 2009). Young people evaluate their health status depending on their peers whilst old people evaluate their health status depending on their age and health expectations (Jylhä, 2009). Literature on self-health assessment has also indicated that the perceptions of health or the health expectations of people who live in poor environments are different from those of people who live in good environments such as urban areas (Browning and Cagney, 2002; Wen, Hawkley and Cacioppo, 2006; Poortinga, Dunstan and Fone, 2008). Poor people or people who live in poor environments tend to report that they have good health because they get accustomed to their poor environment, whilst people in the urban areas tend to report poor health because they are in close contact with health service providers (King *et al.*, 2004). Since SRH is used by various age groups and poverty levels in Malawi, it is important to evaluate the self-reported disabilities to understand if there are any variations in the reporting among the population sub-groups.

This chapter aims to address the issue of disability measurement by examining consistency in disability reporting among Malawian people. This is based on the hypothesis that people's reporting contributes to discrepancies in disability estimates. The analysis will be based on people's ordinal (categorical) responses to the eight health domains of ICF framework, which were collected during the 2003 Malawi World Health Survey (MWHS-2003). Knowledge of the consistency of people's valuations is vital because it provides evidence on the accuracy of data collected during population censuses or surveys.

4.2 Proposed data and method for assessing the self-reported measurement of disability

4.2.1 Data used to address disability measurement issues

The 2003 Malawi World Health Survey was used to assess the self-reported measurement of disability in Malawi. It was a cross-sectional survey developed by the World Health Organization (WHO), to monitor critical health outcomes and health systems through the fielding of a valid, reliable and comparable household survey instrument. This survey is a nationally representative survey which randomly collected information from 5,297 men and women aged 18 years and above (World Health Organization, 2003). Information from survey participants was collected using two questionnaires, the household and the individual. The household questionnaire collected information on household characteristics, health insurance coverage, health expenditure and household wealth. The individual questionnaire collected information on socio-demographic characteristics, health state description, health state valuations, risk factors, chronic conditions, mortality, health care utilisation and health system responsiveness (World Health Organization, 2003).

The analysis for this chapter concentrates on the "health state description and health state valuations" sections of the individual questionnaire. In the health state description section, participants were asked to assess their functioning based on eight health domains of the ICF framework. The health domains included; mobility, self-care, pain and discomfort, cognition, vision, interpersonal activities, sleep and energy, and affect (depression or anxiety). Responses to the self- assessment questions for each domain were in the form of ordered categorical (ordinal) responses. For example on mobility they were asked, "*Overall in the last 30 days, how much difficulty did you have with moving around?*", and their responses were obtained on a scale of 1 to 5, where (1=none, 2=mild, 3=moderate, 4=severe, 5=extreme/cannot do). To correct for differences in the understanding and use of the ordinal responses which is sometimes known as interpersonal incompatibility, participants were also asked to evaluate the health state of hypothetical persons in addition to the self-assessment questions. Questions referring to the hypothetical persons were formulated in the same way as the self-assessment questions and were answered on a five point scale as the self-assessment question (1=none, 2=mild, 3=moderate, 4=severe, 5=extreme/cannot do). **Box 4.2:1** presents the hypothetical stories or anchoring vignettes of the mobility domain. Responses to the hypothetical stories or anchoring vignettes was collected from the survey participants by dividing the sample into four sets and each set responded to vignettes of two health domains. The four sets were set A (mobility and

affect), set B (pain and discomfort and personal relationships), set C (vision and sleep and energy) and set D (cognition and self-care). Each set consisted of 1327 participants. To provide a detailed description of the health domains and the anchoring vignettes, excerpts of the MWHS-2003 individual questionnaire and anchoring vignettes have been attached in appendix D1 and D2.

Box 4.2:1 Vignettes for the Mobility Domain

 [Mary] has no problems with walking, running or using her hands, arms and legs. She jogs 4 kilometres twice a week.

[Anton] does not exercise. He cannot climb stairs nor do other physical activities because he is obese. He is able to carry the groceries and do some light household work.

[David] is paralysed from the neck down. He is unable to move his arms and legs or to shift body position. He is confined to bed.

[Rob] is able to walk distances of up to 200 metres without any problems but feels tired after walking one kilometre or climbing up more than one flight of stairs. He has no problems with day-to-day physical activities, such as carrying food from the market

[Vincent] has a lot of swelling in his legs due to his health condition. He has to make an effort to walk around his home as his legs feel heavy.

4.2.2   Anchoring vignettes

The literature on ordinal (categorical) responses to abstract concepts like health or disability has demonstrated that categorical responses are not readily comparable across sub-population groups. This is due to differences in understanding and use of ordinal responses which often result in shifts in response category cut-off points (Tandon *et al.*, 2003; King *et al.*, 2004). Theoretically, observed response categories are continuous and represent an underlying unobserved latent variable (King *et al.*, 2004). For example, when a participant is asked to report their difficulties in concentrating or remembering things, the understanding is that concentrating or remembering is an abstract idea that is continuous and the participant translates this continuous variable into a categorical variable when choosing the response categories. Therefore, the cut-off points for each categorical response are threshold levels on the latent variable that indicate transition from one observed categorical response to another (Manor, Matthews and Power, 2000; Tandon *et al.*, 2003).

The disparity in the use of response category cut-off points occurs due to differences in health expectations, interpretations of the self-assessment question, culture, age, level of education and gender (Tandon *et al.*, 2003) . For example, a 65-year-old woman whose health expectation is low may describe herself as having mild pain when experiencing pain while rising up from a chair, whilst a 25-year-old woman whose health expectation is different from that of the older woman may describe herself as having moderate pain when she experiences the same pain. This difference in use of the response category cut-off points is called differential item functioning (DIF) and if not properly adjusted may provide misleading results (Salomon, Tandon and Murray, 2004).

To correct for the differential item functioning in ordinal categorical responses, researchers have developed the technique of anchoring vignettes. This technique involves the use of hypothetical stories that provide a concrete description of the level of ability in a given health domain, that participants evaluate in relation to the main research question and on the same categorical response scale as the main self-report question (Tandon *et al.*, 2003; Salomon, Tandon and Murray, 2004). The main objective of using this technique is to produce ratings for the hypothetical levels in a given domain that reflect individual norms and expectations for health, that participants use when evaluating their own health state (Salomon, Tandon and Murray, 2004). Anchoring vignettes, in this case, fix the level of ability, such that variations in categorical responses are attributable to variations in response category cut-off points and not due to health expectations (Tandon *et al.*, 2003). The use of anchoring vignettes also assists in identifying the effect of socio-demographic characteristics (e.g. age and sex) on the level of the measured underlying latent variable and on the response category cut-off points (Tandon *et al.*, 2003; King *et al.*, 2004).

Anchoring vignettes have long been used in social sciences to improve the validity of self-reported observations in studies of disability, attitudes, perceptions, beliefs and norms. Vignettes have been used to enhance the validity and cross-cultural comparability of political efficacy measures (King *et al.*, 2004), and to understand people's attitudes and beliefs with regard to health care (Hughes and Huby, 2002). They have also been used as a socio-economic calibration scale for self-rated health in Brazil (Damacena, Vasconcellos and Szwarcwald, 2005) and to examine differences in health expectations (such as mobility) in the World Health Survey (Üstün *et al.*, 2001). In all these studies, anchoring vignettes have proven to be a powerful tool for reducing bias, increasing efficacy and improving the interpersonal comparability of self-reported measures (King *et al.*, 2004). Anchoring vignettes have also been shown to be a reliable instrument for assessing the influence of health expectations and other socio-demographic characteristics on self-ratings of health (Tandon *et al.*, 2003; Salomon, Tandon and Murray, 2004). Nonetheless,

there are limitations to using of anchoring vignettes because of their basic assumptions and the wording of hypothetical stories.

There are two basic assumptions in the use of anchoring vignettes. The first assumption is *response consistency*, which implies that the participant should use the response categories of a particular question in a similar way when evaluating the hypothetical stories and when providing their self- assessments (King *et al.*, 2004; Rice, Robone and Smith, 2011). The second one is *vignettes equivalence*, which implies that the underlying domain level represented in each vignette should be understood in approximately the same way by all the participants, irrespective of their age, sex, education, country of residence or other demographic characteristics (Salomon, Tandon and Murray, 2004). The problem with these assumptions is that the probability of participants not understanding the research questions the same way is high due to vignette wording and design of the study. For example, people with cognitive problems or learning difficulties experience concentration span problems with long written vignettes compared to other population sub-groups, thus their understanding of the vignettes may be different to that of other people (Hughes and Huby, 2002). In terms of age, young people are less likely to relate to hypothetical stories of older people than older people themselves (Hughes and Huby, 2002; Rice, Robone and Smith, 2011).

These difficulties in understanding the wording of vignettes cannot be solved through the use of anchoring vignettes alone since vignettes mainly focus on correcting response category differentials (Hughes and Huby, 2002; King and Wand, 2007). Thus, there is a need to develop short worded vignettes to accommodate those with cognitive problems and to match the vignette characters with the survey participants to reduce bias (Hughes and Huby, 2002; Salomon, Tandon and Murray, 2004; King and Wand, 2007). The anchoring vignettes used in this study were developed in such a way that they are short-worded and the characteristics of the hypothetical persons are very similar to those of the participants. This ensures the adherence of the survey to the key assumptions of anchoring vignettes.

The similarity of the hypothetical persons to the survey populations was formally assessed through the use of test-retest reliability and rank order correlation tests (Üstün *et al.*, 2003). Before the commencement of the World Health Survey as discussed in section 3.3 of the methodology chapter, the survey instruments, which comprised of heath state valuations and anchoring vignettes were used in the WHO Multi-Country survey. Data collected from the Multi-Country Survey was then used to assess the reliability of the anchoring vignettes in consistently measuring health across populations. A test-retest reliability of the anchoring vignettes across the various populations, produced Kappa Statistics which were close to 1 (1=perfect agreement,

0=level of agreement expected by chance) (Salomon, Tandon and Murray, 2001). This indicated that the hypothetical persons described in the anchoring vignettes were similar to those of the populations understudy. The rank order correlation tests also produced correlation coefficients that were close to 1. The rank order correlation results also demonstrated that the anchoring vignettes conveyed the same concepts and the same fixed domain levels across the participants (Salomon, Tandon and Murray, 2001).

4.2.3   Proposed variables for examining self-reported disabilities

Dependent variables

The study aims to assess self-reported measurement of disability in Malawi. The variable of interest, in this case, is functional disability, which has been measured based on the eight health domains of the ICF framework (mobility, self-care, pain and discomfort, affect, cognition, interrelationships, sleep and energy and vision). These health domains are a robust measure of disability because they measure disability as a dynamic interaction between health conditions and contextual factors (Jette, 2006; Whiteneck, 2006). The eight health domains are presented in Box 4.2:2

Box 4.2:2 Eight Health Domains of the ICF frameworks used in the MWHS-2003

Mobility
Q1. Overall, in the last 30 days, how much difficulty did you have with moving around?
Q2. In the last 30 days, how much difficulty did you have in vigorous activities such as running 3km (or equivalent) or cycling?

Self-care
Q1. Overall, in the last 30 days, how much difficulty did you have with self-care, such as washing or dressing yourself?
Q2. In the last 30 days, how much difficulty did you have in taking care of and maintaining your general appearance (e.g. grooming, looking neat and tidy etc.)

Pain and Discomfort
Q1. Overall, in the last 30 days, how much of bodily aches or pains did you have?
Q2. In the last 30 days, how much bodily discomfort did you have?

Cognition
Q1. Overall, in the last 30 days, how much difficulty did you have with concentrating or remembering things?
Q2. In the last 30 days, how much difficulty 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 etc.)?

Interpersonal relationships
Q1. Overall, in the last 30 days, how much difficulty did you have with personal relationships or participation in the community?
Q2. In the last 30 days, how much difficulty did you have in dealing with conflicts and tensions with others?

Vision
Q1. Do you wear glasses or contact lenses?
Q2. In the last 30 days, how much difficulty did you have in seeing and recognizing a person you know across the road (i.e. from a distance of about 20 meters)?
Q3. In the last 30 days, how much difficulty did you have in seeing and recognizing an object at arm's length or in reading?

Sleep and Energy
Q1. Overall, 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?
Q2. In the last 30 days, how much of a problem did you have due to not feeling rested and refreshed during the day (e.g., feeling tired, not having energy)?

Affect
Q1. Overall, in the last 30 days, how much of a problem did you have with feeling sad, low or depressed?
Q2. Overall, in the last 30 days, how much of a problem did you have with worry or anxiety?

Independent variables

Place of residence, age of participant, presence and absence of impairment, sex of participant and level of education are used as explanatory variables in this analysis. Place of residence has been chosen as an explanatory variable because it influences an individual's health assessment. According to Wen et al (2006) perception of place of residence quality in terms of physical, social and service environments significantly affects self-rated health of an individual. People who negatively perceive their neighbourhood environment (unaffordable and uncomfortable housing, noise, crowdedness and poor air quality) are more likely to report poor health than those with a positive attitude (Wen, Hawkley and Cacioppo, 2006).

Unlike place of residence, age of participant has a complex relationship with self-reported disability. The complex nature of the relationship comes in because the frequency of health problems differs between age groups (Cheng, Fung and Chan, 2007; Jylhä, 2009). Young people experience fewer disabling conditions than older people, thus they are expected to report fewer difficulties in functioning. Older people on the other hand, experience high levels of disabling conditions and are expected to report high levels of difficulty, but they report low levels of difficulty due to their low expectations of health (Jylhä, 2009). The complex relationship between age and the self-reported disabilities means that it is difficult to predict the variation in reporting between young and old people. Therefore, in this study the assumption is that there is a linear relationship between age and the reporting of functional difficulty, in such a way that the older the respondents the more likely they are to report difficulty in functioning. For example, in this study, a regression analysis was conducted to check if there is any variation in the reporting of mobility difficulty among persons with different age groups. Age in this regression model was in three formats, as a continuous variable, as age squared and as a categorical variable with categories (young people=18 to 34) and old people (35 and above). The results of the regression model presented in table 4.1 in appendix B, indicate that age squared and age as a categorical variable do not significantly predict the variation in the reporting of mobility difficulty. Only age as a continuous variable significantly predicted the variation in reported mobility difficulty. These results obtained from the regression model demonstrated that there is a linear relationship between age and the reporting of functional difficulties, that is why age was included as a continuous variable in the model.

Impairment is also an important explanatory variable because it limits other people's ability to perform their socially acceptable daily activities (World Health Organization, 1980; Chamie, 1989). The impairment variable in this study has been derived from interviewer observations of the 2003 Malawi World Health survey. During the data collection process, interviewers were

asked to record whether their participant had a hearing or vision problem; used a wheelchair; used a cane or crutches or walker; had difficulties in walking; had a paralysed arm, hands or legs; coughed continually; had shortness of breath; had a mental problem or other health problems; and had an amputation of a limb or part of a limb. Responses to all these questions were recorded into dummy variables of 0 and 1 using STATA (a statistical package for analysing data). For example, the observation on the visual problem was recorded 0= no problem, 1=has a vision problem. The responses to each dummy variable were then added up to create one variable with different levels of problems or impairments (i.e. 0, 1, 2 … up to 8 impairments). The new variable was then recorded in just two categories; category 0 was for those who had no problem or no impairment; category 1 was for those who had one or more problems or impairments. The impairment variable with multiple categories was recorded into a dummy variable because the other categories had smaller proportions of respondents. For example, there were only 4 out of 5297 people who had visual problems. The smaller number of units in the variable, meant that the regression outcome will have some errors. Therefore to remove the errors that may have occurred due to smaller number of cases, the impairment variable was recorded into a binary variable with category 1 representing presence of an impairment and category 0 no impairment. The limitation of combining all types of impairments into one category is that different types of impairments have different effects on access to sexual and reproductive health services. For example, a person with visual problems may experience difficulties in access SRH services at the health facility if there are no rails or steps to guide him whilst a person on a wheelchair may require the presence of ramps to access the health facility for sexual and reproductive health services.

Sex of a participant and level of education are socio-demographic variables that also determine a person's ability to rate their health functioning. For example, women tend to report higher levels of disability compared to men, because they spend a high proportion of their reproductive life (15 to 49) visiting health facilities for health and health care utilization. This behaviour helps them learn to pay close attention to and acknowledge pain and discomfort, unlike men who are more likely to ignore such symptoms (Verbrugge, 1985; Merrill *et al.*, 1997; Friedmann, Elasy and Jensen, 2001).

 Level of education, like age, has a complex relationship with self-reported disability (Dowd and Zajacova, 2007; Liu and Hummer, 2008; Zhang *et al.*, 2010). Among adult populations, people with higher levels of education are more likely to report poor health compared to those with lower levels of education. However, Liu et al (2008) and Zhang et al (2010) have noted that among young generations, there is no statistically significant difference in self-rated health among those with tertiary education and primary education. With regards to this study, a small proportion of

the respondents had finished their secondary or post-secondary education. More than 70% had less than primary education. For example only 0.17% had college or post-secondary education. This study therefore, examined the effect of both the categorical and continuous education variable on self-reporting. The results presented in table 4.2 in appendix B indicate that there is no significant difference in the reporting among people of different educational level. This results led to the use of a continuous education variable in the regression models. Further to the educational status of the respondents, self-reported disability has also been found to be associated with the economic status of the respondents (King *et al.*, 2004; Dowd and Todd, 2011). People with a higher economic status have been found to reported higher levels of disability compared to people with low economic status. According to Iburg et al (2001), wealthier people tend to report higher levels of disabilities because they believe that they should be healthier than other people of the lowest quintile. Poor people on the other hand tend to report less disabling conditions because they have low health expectations and because they get accustomed to their poor economic conditions (King *et al.*, 2004; Dowd and Todd, 2011). In this study the wealth status of an individual has also been included as an explanatory variable to assess its relationship with the reporting of various health domains. When modelling the various domains, wealth has been included as a continuous variable because there was no significant difference in the prediction power of the continuous and categorical wealth index.

4.2.4   Analysis of data using Anchoring Vignettes and Compound Hierarchical Ordered Probit modelling (CHOPIT)

4.2.4.1 Descriptive statistics

Data analysis for this chapter included descriptive and multivariate analysis in STATA and Anchors Package in R. Descriptive analysis was conducted using cross-tabulations. The descriptive analysis aimed to describe the basic features of the data and provide a summary of the explanatory variables (age, sex, impairment and functional limitations). The descriptive analysis involved cross-tabulating sex of participant with impairment, age, place of residence and level of education. The disadvantage of descriptive analysis is that it does not correlate or create any type of statistical modelling relationship among variables that might lead to inferred conclusions or hypotheses (Trochim and Donnelly, 2001).

4.2.4.2 Vignette equivalence and consistency

The tests of vignette equivalence and consistency were achieved through mean summary test statistics in STATA. The test statistics examined the distribution of the vignette ratings in the survey. Consistency in rank ordering between young and old people in relation to the overall

average country ordering was used as an indicator of same level perception of anchoring vignettes (Salomon, Tandon and Murray, 2004).

These tests are vital in this study because they help to remove differential item functioning (DIF) and personal incomparability, which occurs due to differences in individual characteristics. In comparing young and old people, the aim is to measure the difference in understanding of the research questions or the wording of the research tools. Participants' responses may be affected by a combination of individual disability, differences in health expectation, culture or age and random measurement error. Therefore, tests of vignette equivalence and consistency help to remove response differences that occur due to health expectation, culture or age, thus creating DIF-free responses that are only affected by actual level of disability and random measurement error (King *et al.*, 2004; Hopkins and King, 2010). The results from the analysis then provide evidence that all participants understood the level of disability described in the hypothetical stories at the same level, and that the vignettes can be used as a scale for re-scaling the self-assessment responses. The limitation of this analysis is that its validity is controlled by the investigator through research design, definition of the concepts, development of questions, pre-testing and approach used in data collection (King *et al.*, 2004; Salomon, Tandon and Murray, 2004).

4.2.4.3 Relative ranking

This study further analysed the consistencies in rating between self and vignette questions. Relative ranking was conducted to examine how each participant was using the survey response scale in responding to self-assessment and vignette questions. This analysis was conducted under the assumption that there was a "true" ordering of the vignettes and that participants' choice of a categorical response on the self-assessment question was based on specific vignettes (Wand, King and Lau, 2011). Examination of relative rankings of participants was conducted in relation to the sex of the participant.

Model of relative ranks

 In relative ranking, y_i is taken to be the categorical self-assessment question for participant i (i=1,…, n) and z_{ij} to be the categorical survey response for participant i , on the vignette j (j=1,…, J). Then for all participants with identical ordinal rankings on all vignettes ($z_{j-1}<z_j$, for j=2,…, J), a DIF-free self-assessment variable C_i is created, such that

$$C_i = \begin{cases} 1 & if \ y_i < z_{i1} \\ 2 & if \ y_i = z_{i1} \\ 3 & if \ z_{i1} < y_i < z_{i2} \\ \vdots & \vdots \\ 2J + 1 & if \ y_i > z_{ij} \end{cases} \qquad (4.1)$$

For all vignettes with no identical ordinal ranking, their responses are grouped together and treated as ties. If the tied vignette responses are equal to the self-assessment response the values for C_i become an interval or a censored value such that C_i is treated as a vector rather than a scalar variable (King *et al.*, 2004; Wand, King and Lau, 2011). In cases where there are very few survey response categories with which to differentiate among categories of the variable C_i, the categories are collapsed. The created variable C_i is then analysed to produce bar charts or bar-graphs (King *et al.*, 2004; Wand, King and Lau, 2011).

In this study, participants were given five vignettes (j=5) for each health domain question, to evaluate in addition to the self-assessment question. Therefore, using equation (4.1) it meant that the total number of categories for the DIF-free variable C_i was supposed to be 11, i.e.

$$C_i = 2j + 1 \qquad (4.2)$$

However, there were only a few participants that rated themselves in relation to vignettes with severe and extreme (cannot do) functional limitations. Severe and extreme categories were thus collapsed such that the generated DIF-free variable had 7 response categories. The variable was then analysed using Censored Ordered Probit model. This model is a parametric model for breaking ties or intervals in non-parametric ranks (Wand, King and Lau, 2011). The Censored Ordered Probit model was used in analysing the DIF-free variable because the variable had interval cases. The Censored Ordered Probit model was also used instead of the ordered Probit model because "it uses all available information in the self-assessment, vignettes and explanatory variables to estimate the distribution of frequencies for the vector–valued observations rather than merely assuming an arbitrary distribution", (King and Wand, 2007).

4.2.4.4 CHOPIT: Compound Hierarchical Ordered Probit model

A CHOPIT model is a method for analysing ordinal survey responses which vary among population groups due to differences in interpretation of the research question (Rabe-Hesketh and Skrondal, 2002). It models the self-assessment responses through use of anchoring vignettes. The responses to the vignettes are used as anchors for the self-assessment question by identifying a mutual threshold that has coefficients that are similar to those of the self-assessment question, vignettes and the explanatory variables. The CHOPIT model thus lets the thresholds (which turn

the unobserved continuous variable to be measured into an observed categorical response) vary over the participants as a function of measured explanatory variables (King *et al.*, 2004).

CHOPIT model has been chosen instead of the standard Ordered Probit model because the basic assumption of fixed threshold levels of the standard Ordered Probit model does not hold with ordinal responses whose threshold levels vary depending on individual interpretation of the research question (Tandon *et al.*, 2003). The CHOPIT model also enables the researcher to measure the underlying continuous responses which are transformed into observed categorical responses   (Tandon *et al.*, 2003; King *et al.*, 2004), and allows the researcher to include multiple self-assessment questions for the same underlying concept (King *et al.*, 2004).

When analysing ordinal survey responses using the CHOPIT model, the model first estimates the cut-off points of the responses scale from the anchoring vignettes and uses these cut-off points to estimate the responses for the self-assessment questions. Thus, the model has two components - the anchoring vignettes and the self-assessment component.

Vignette component:

In modelling the responses to the anchoring vignettes it is assumed that each hypothetical person in the anchoring vignettes has an unobserved level of the latent trait (or disability) that is continuous, and unbounded which survey participants translate into observed categorical response scale (King *et al.*, 2004). The unobserved level of disability for the hypothetical person described in anchoring vignette j may be denoted as θj (for j=1,…J). If a participant in the sample has an index ɨ and using the likelihood function of an Ordered Probit model (i.e. fixed cut-off points or threshold values), it can be assumed that there is an unobserved latent variable Y_{ij}^{v*} distributed with mean μ_{ij}^{v} and variance 1.   In mathematical terms, the vignettes component is described as;

$$Y_{ij}^{v*} \sim N\left(\mu_{ij}^{v}, 1\right), \qquad\qquad \text{ɨ=1,....., N; j=1,…, J} \qquad\qquad (4.3)$$

$$\mu_{ij}^{v} = z_{i}' \qquad\qquad\qquad\qquad (4.4) \qquad \text{(Tandon } \textit{et al.}\text{, 2003)}$$

Where;

ɨ refers to the participant

j refers to the vignette number

v subscript indicates that this is the vignette component of the model

Z_i Is a vector of explanatory variables for each of the J-1 vignettes

The survey participants then turn the unobserved continuous latent variable Y_{ij}^{v*} into a categorical response via the observation mechanism, which is mathematically described as

$$y_{ij}^v = k \quad if\ \tau_i^{k-1} \le Y_{ij}^{v*} < \tau_i^k; \quad For\ \tau_i^0 = -\infty, \tau_i^5 \quad \forall\ i, j, \&\ k = 1, ..., 5 \quad (4.5)$$

With a vector of thresholds or cut-off points that vary over the observations as a function of the explanatory variables

$$\tau_i^k = \gamma^k X_i'\ ; \quad Where\ \ \tau_i^1 < \tau_i^2 < \tau_i^3 < \tau_i^4 \quad (4.6)$$

Self-assessment component:

The self –assessment component on the other hand, utilizes information from the participant's main self-report question (the one that is directly linked to the vignettes). In modelling the self-assessment question, it is also assumed that the survey participant has an unobserved disability level (latent trait) that is continuous, unbounded and unidimensional that translates into an observed categorical response scale when the participant answers the survey question. In other words, there exists an unobserved latent variable Y_i^{s*} which is normally distributed with mean μ_i^s and variance δ^2 (Rabe-Hesketh and Skrondal, 2002) The s superscript on the latent variable indicates that the variable relates to the self-assessment question. The modelling of the unobserved latent variable Y_i^{s*} for the self-assessment questions is slightly different from the standard Ordered Probit model, because the cut-off points of the anchoring vignettes are now used to estimate the probabilities associated with the self-assessment questions (e.g. the mobility question) (Rabe-Hesketh and Skrondal, 2002; King *et al.*, 2004). Since the cut-off points or the threshold values stem from the anchoring vignettes, there is no need to set the variance value to 1 and it is now possible to obtain the variance of the latent variable. In mathematical terms, the model can be written as:

$$Y_i^{s*} \sim N(\mu_i^s, \delta^2)\ ; \quad i=1,...,N \quad (4.7)$$

$$\mu_i^s = W_i \beta' \quad (4.8)$$

 The survey participant then turns the unobserved continuous disability (latent trait) into the observed categorical responses of the self-assessment question such that;

$$y_i^s = k\ \ if\ \tau_i^{k-1} \le Y_i^{s*} < \tau_i^k; \quad For\ \tau_i^0 = -\infty\ , \tau_i^5 = \infty,\ \forall\ i, k = 1, ...,5 \quad (4.9)$$

(Tandon *et al.*, 2003)

The estimated threshold values or cut-off points are a function of the explanatory variables as expressed in equation 4.6

4.3 Results of the technique of anchoring vignettes and Compound Hierarchical Ordered Probit modelling

4.3.1 Descriptive analysis

This section provides a basic summary of the demographic characteristics of the 5297 MWHS-2003 survey participants and compares their characteristics to the 32,040 participants of the 2015/16 Malawi Demographic and Health Survey. The results in table 4.3:1 indicate that 6% of the population had an impairment. The impairment variable includes hearing, vision, wheelchair users, those who use walkers, have mental problems and paralysis. The table indicates that close to half of the sampled population were aged between 18 and 29 (45%) and that 10.16% of the sampled population were aged 60 and above. The table further indicates that the age distribution of the sample by sex was not statistically significant at the 95% level of significance with an associated p-value of p<0.05.

With regards to the urban/ rural distribution, the table demonstrates that close to (85%) of the population in 2003 were living in rural areas and only (15 %) were living in urban areas. This population proportional distribution has changed from (85%) in 2003 to (82%) in 2015 in rural areas and from (15%) in 2003 to (18%) 2015 in urban areas (NSO, 2016a). In terms of place of residence distribution by sex, the table indicates that the proportion of women who were living in the rural areas was very similar to that of men with proportional distributions of (85.9 %) and (83.2%) respectively.

Apart from age and place of residence, table 4.3:1 further demonstrates that half of the adult population (50.7%) in 2003 had not finished their primary education, less than a fifth (17.6%) had primary education and less than a tenth (6.6%) had either secondary or tertiary education. Comparing the level of education by sex, the descriptive results indicate that men were more educated than women. More than (50 %) of men had some primary education compared to women whose percent distribution was (49.3 %). Currently the MDHS 2015-16 reports that 65.3% of men in the country have some primary education and that 67.1% of women have some primary education (NSO, 2016b).

With regards to marriage, the results in table 4.3:1 indicate that (74%) of men were either married or cohabiting compared to (68.7 %) of women. Furthermore, the table indicates that a high proportion of women were either divorced (12.6%) or widowed (11.1%) compared to men (3.4% and 2.5% respectively).

Table 4.3:1 Percent distribution of the 2003 Malawi World Health Survey participants

Background characteristics	Women	(SE)	Men	(SE)	Total	Number	Chi square test (P-value)
Impairment							
No impairment	94.0	0.0	95.0	0.0	94.0	4958	
Has an impairment	6.0	0.0	5.0	0.0	6.0	339	
Total	100		100			5297	p=0.25
Age							
18-29	44.5	1.2	45.9	1.4	45.2	2393	
30-44	29.2	1.2	28.4	1.2	28.8	1526	
45-59	16.2	1.0	15.5	1.1	15.8	839	
60+	10.2	0.1	10.2	0.1	10.2	538	
Total	100		100		100	5297	P= 0.86
Place Residence							
Urban	14.1	0.1	16.8	0.1	15.4	822	
Rural	85.9	0.1	83.2	0.1	84.6	4474	
Total	100		100		100	5297	P=0.04
Level of Education							
No Education	32.9	0.1	16.9	0.1	25.1	1329	
Less than Primary	49.2	0.1	52.3	0.1	50.7	2685	
Primary	13.9	0.1	21.6	0.1	17.6	933	
Secondary +	4.1	0.1	9.3	0.1	6.6	350	
Total	100		100		100	5297	P=0.00
Marital status							
Never married	7.7	0.1	20.1	0.1	13.7	727	
Married /Cohabiting	68.7	0.1	74.0	0.1	71.3	3776	
Separated/Divorced	12.6	0.1	3.4	0.0	8.1	430	
Widowed	11.1	0.1	2.5	0.0	6.9	363	
Total	100		100		100	5297	P=0.00
Row Percentage	51.2	0.1	48.8	0.1			

In addition to the background characteristics, the study also analysed the responses to the eight health domains of the ICF framework. Figure 4.3:1 provides a summary of these responses by presence or absence of an impairment. The domains include mobility, self-care, pain and discomfort, cognition, interpersonal activities, vision, sleep and energy and affect. The results in figure 4.3:1 demonstrate that a high proportion of persons with impairments experienced mild to extreme levels of functional limitation in all the eight health domains compared to those without an impairment.

On the mobility domain, the results in figure 4.3:1 demonstrate that more than 70% of persons without impairments reported having no difficulties in mobility compared to 30% of those with

impairments. Among those with an impairment, close to 60% reported having either mild, moderate or severe difficulties in mobility compared to those without an impairment.

With regards to pain and discomfort, figure 4.3:1 illustrates that among the 80% of persons with impairment who reported experiencing pain and discomfort in the 30 days before the survey, 30% reported to have experienced severe levels of pain and discomfort. The figure further illustrates that even among persons without an impairment there were some participants who reported having experienced pain and discomfort (50%). Among the 50% of participants with no impairment who reported experiencing pain and discomfort, more than 10% reported having experienced severe levels of pain and discomfort.

Further to experiences of pain and discomfort, figure 4.3:1 illustrates that persons with impairment reported more experiences of functional limitations in cognition, vision, sleep and energy and affect, compared to persons without impairments. Concerning cognition, the figure illustrates that close to 20% of persons with impairments reported having severe difficulties in remembering things compared to 5% of those without impairments. More than 20% of persons with an impairment also reported having experienced anxiety or depression compared to 10% of those without impairments.

Figure 4.3:1 Responses to the eight health domains by presence or absence of an impairment
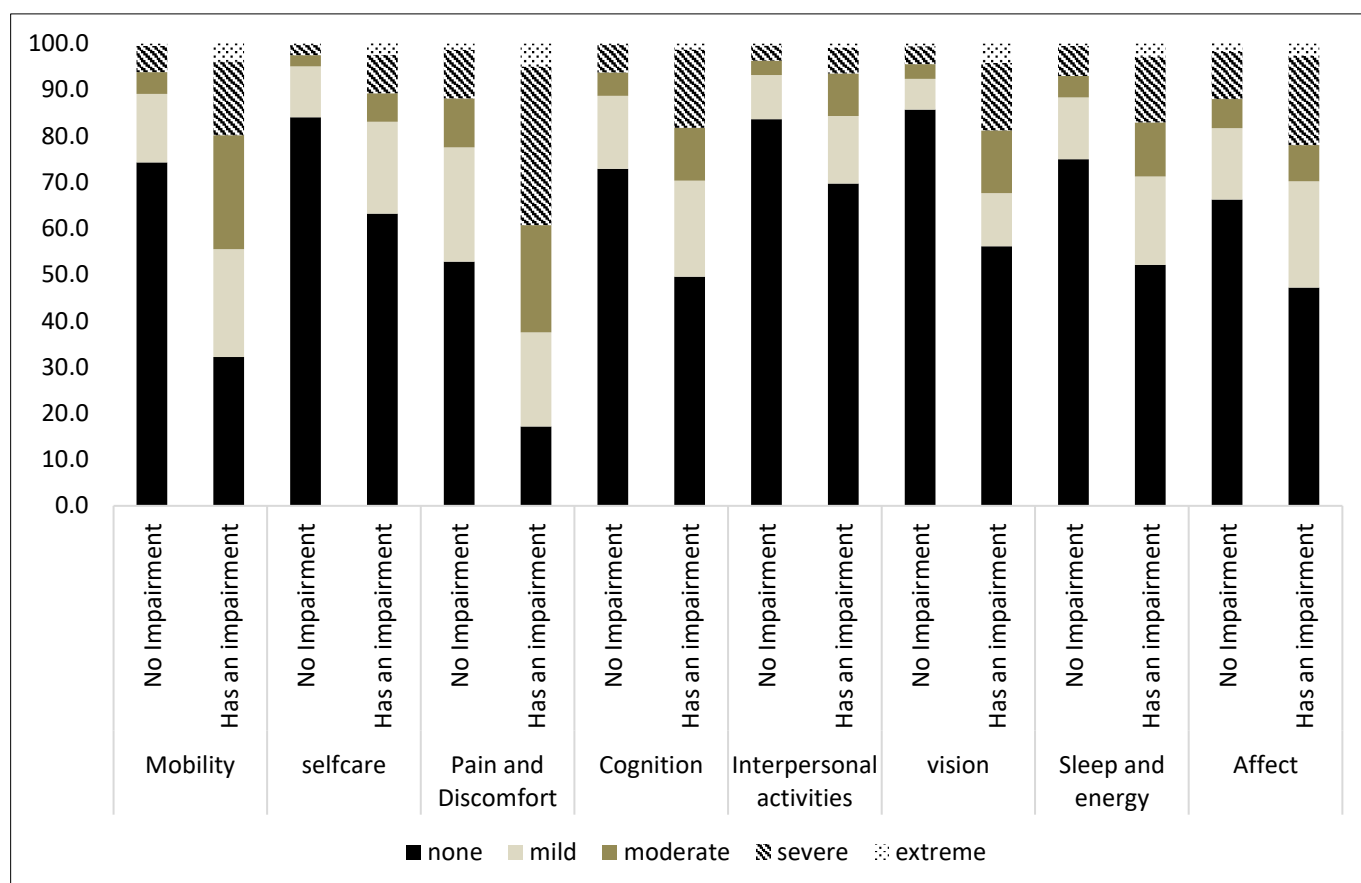
4.3.2   Vignette equivalence and consistency

In addition to the demographic characteristics of the survey participants, this study also assessed the ordering of the anchoring vignettes of each health domain. An analysis of vignette equivalence, in terms of rank ordering indicates, that both young participants (18 to 35 years) and older participants (36 and above) rank ordered the anchoring vignettes in the same order as the overall country ordering. This indicates that both young and old participants understood the concept and level of disability described in the hypothetical stories. For example, the mobility results in Figure 4.3:2 indicate that the rank ordering of vignettes in the two questions of the mobility domain was the same among the young and older participants. The rank order of Mary was the same among young and old participants, and the same applied to Rob, Anton, Vincent and David. Nonetheless, there were some participants who ranked the five vignettes with the same scale (such as 1,1,1,1,1) or two distinct ranks such as (1,4,4,4,4) these participants were removed from the sample. The participants were removed from the sample to improve the accuracy and validity of the CHOPIT model results. Table 4.3:2 presents a summary of the number of persons who were removed from each health domain.

Figure 4.3:2 Rank ordering of the mobility vignettes by age of the participant (MWHS-2003)
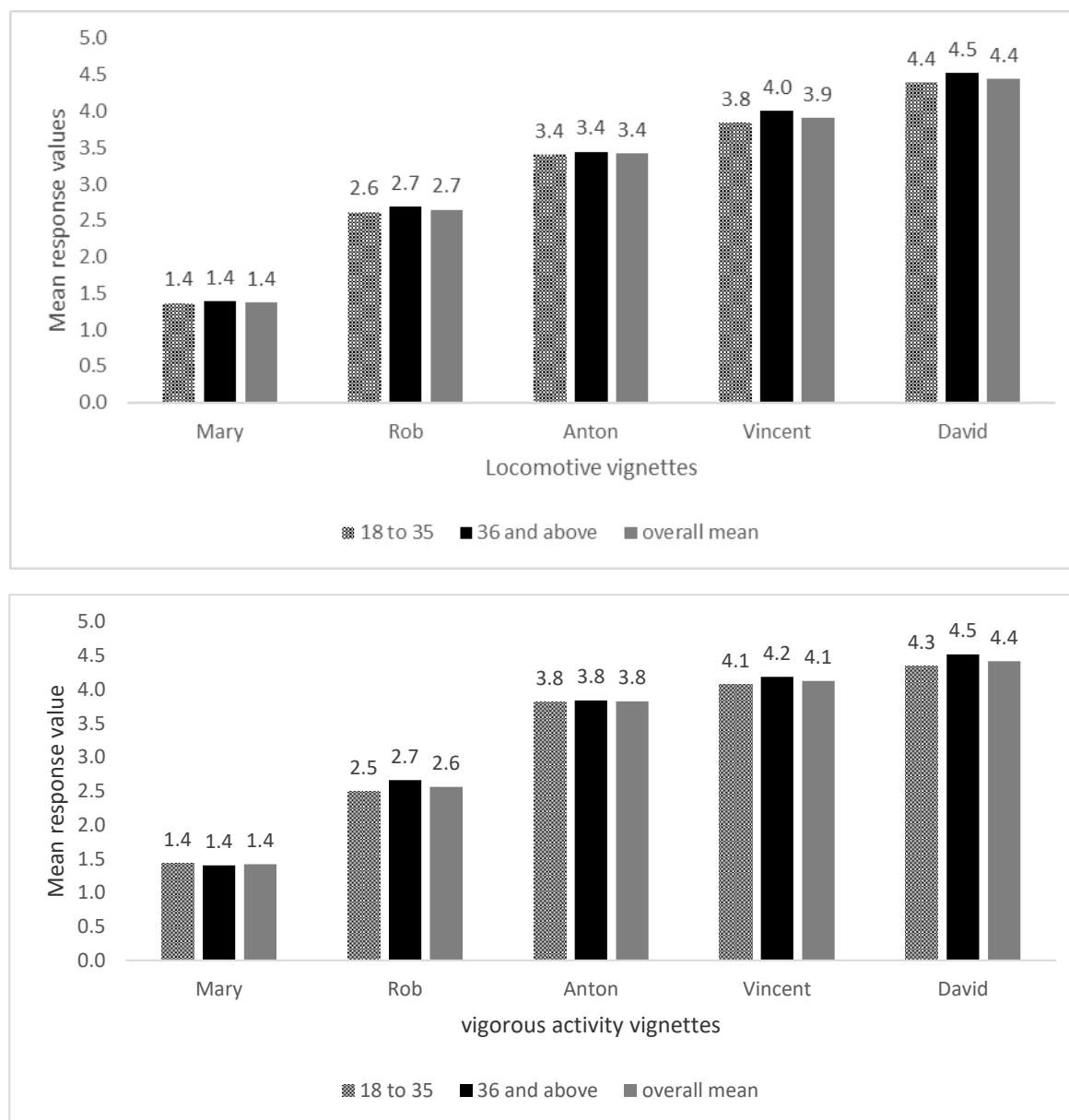
Rank ordering of vignettes for two questions of the mobility domain (Q1: Overall in the last 30 days, how much of a problem did [name of person] have with moving around? Q2: In the last 30 days, how much difficulty did [name of person] have in vigorous activities, such as running 3km (or equivalent) or cycling?)

Table 4.3:2 Number of persons removed from each health domain

Health Domain	Original Sample	Proportion with one or two distinct vignette responses	Number with one or two distinct vignette responses	Final sample
Mobility	1327	9.9	132	1195
Affect	1327	13.8	183	1144
Pain and Discomfort	1327	11.2	148	1179
Personal relationships	1327	15.0	199	1128
Vision	1327	15.4	204	1123
Sleep and Energy	1327	14.1	187	1140
Cognition	1327	16.2	215	1112
Self-care	1327	3.6	48	1279

Further to the presentation of the study participants who had one or two distinct responses to the anchoring vignettes ,table 4.3:3 present the background characteristics of thestudy participants who responded to the anchoring vignettes of the mobility and affect domain. The results in table 4.3:3 indicate that there were small but non significant differences in the proportion distribution of the sample with one or two distinct vignette responses and those with more that two responses and the overall sample. For example, the proportion of those with no impairments among the sample with one or two vignette responses was 91.&% whilst among those with more than two vignette responses was 94.3% and for the overall sample was 94.3%.

Comparing the participants with one or two distinct responses and those with more than two vignette responses in relation to presence of an impairment, the results in table 4.3: indicates that there were more participants with impairments among those with one or two distinct vignette responses compared to those with more than two responses and the rest of the sample (8.3% compared to 5.7% respectively).

 In terms of age distribution, the results in table 4.3:3 indicates that the age distribution of the participants with one or two distinct vignettes responses was almost similar to that of the participants with more than two vignettes responses, even though there was 2% increase in the proportion of those aged 60 and above.   With regards to place of residence, the results in table 4.3:3 indicates that more than 20% of the respondents with one or two distinct vignettes responses were from the urban areas compared to the 14.7% of those with more than two vignettes responses and the overall sample (16.5%).

Table 4.3:3 Background characteristics of respondents with one or two distinct vignette responses

Background characteristics	Participants with one or two distinct vignette responses	Standard Error (SE)	Participants with more than two vignette responses	Standard Error (SE)	Total	Number
Impairment						
No impairment	91.7	2.2	94.3	0.7	94.3	1251
Has an impairment	8.3	2.2	5.7	0.7	5.7	76
Total	100		100		100	1327
Age						
18-29	45.8	4.0	45.0	1.5	45.4	614
30-44	27.5	3.6	29.8	1.4	29.6	386
45-59	14.4	2.8	14.8	1.1	14.6	190
60+	12.4	2.7	10.4	0.9	10.5	137
Total	100		100		100	1327
Place of Residence						
Urban	23.7	3.4	14.7	1.1	16.5	221
Rural	76.3	3.4	85.3	1.1	83.5	1106
Total	100		100		100	1327
Level of Education						
No education	20.4	3.2	23.8	1.3	23.3	309
Less than Primary	49.7	4.0	46.9	1.5	47.8	634
Primary	20.4	3.4	22.3	1.2	21.6	286
Secondary +	9.6	2.4	7.1	0.8	7.4	90
Total	100		100		100	1327
Marital Status						
Never Married	8.9	2.3	10.9	0.9	10.3	137
Married/Cohabiting	69.4	3.6	68.4	1.4	69.4	921
Separated/Divorced	10.2	2.4	10.8	0.9	10.4	138
Widowed	11.5	2.6	9.9	0.9	9.9	131
Total	100		100		100	1327

4.3.3   Relative Ranking

Having noted that some sample participants gave the same or two distinct responses to the anchoring vignettes, the researcher decided to examine further the data using a relative ranking technique. Relative ranking, as discussed in section 4.2.4.3, was conducted to examine how the survey response scale (1=none, 2=mild, 3=moderate, 4=severe, 5=extreme/cannot do) was used by the participants in relation to self-assessments and vignettes questions. The relative ranking results are presented through a comparative analysis of the responses of the participants who only had one or two distinct responses with those of the participants with more than two distinct responses, in the mobility domain.

Before discussing the results, figure 4.3:3 provides a map for interpreting Vector C values in the Censored Ordered Probit model. The value of 1 relates to participants who perceived their functional difficulty to be better than that of a vignette with no functional difficulty. Survey participants may select a response on the self-assessment question that indicates that their health is better than that of the vignettes with no functioning difficulty because of the wording of the research question or their interpretation of the research question and the response scale. For example, if we have two survey participants, a young adult (aged 25) and an old person (aged 64) who have been given the three mobility vignettes described in box 4.2:1. The old persons may understand the various levels being described in the vignettes, but because of his or her health expectations may decide to assign low response value to the vignettes. The old persons may also perceive himself as having a mobility difficulty that is above that of Anton but below that of David. The young persons on the other hand, may understand the different mobility difficulties being described in the three vignettes, but due to his health expectations and the need to please the researcher may decide to assign high response values to the vignettes. With regards to his own mobility difficulty the young participant may decide to assign himself a low response value which in graphical format may be lower than that of the vignette with no functional difficulty. Therefore to incorporate survey participants who may assign themselves low response values in relation to the anchoring vignettes. The Vector C of the Censored Ordered Probit model start with a value that indicates that $y < z_1$. Where y is the self-assessment value and z_1 is the response to the vignette with no functioning difficulty. Figure 4.3:3 provides a summary of the use of the response scale by the young and old survey participant.

Figure 4.3:3 Use of the response scale by survey participants

Value 2 relates to participants who perceived their functional difficulty to be equal to that of the vignette with no functional difficulty, and value 3 relates to those who perceived their functional difficulty to be less than that of the vignette with no difficulty but not equal to that of the vignette with mild functional difficulty. Value 4, relates to the participants who perceived their functional difficulty to be equal to the vignette with mild functional difficulty. Value 5 relates to the participants who perceived their functional difficulty to be greater than that of the vignette with mild functional difficulty but less than that of the vignette with moderate functional difficulty. Value 6 relates to participants who perceived their functional difficulty to be equal to the vignette with moderate functional difficulty. Value 7 relates to participants who perceived their functional difficulty to be greater than the vignette with moderate difficulty but less than the vignette with severe functional difficulty.

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[2]

Figure 4.3:4 mapping of individual responses in relation to anchoring vignettes
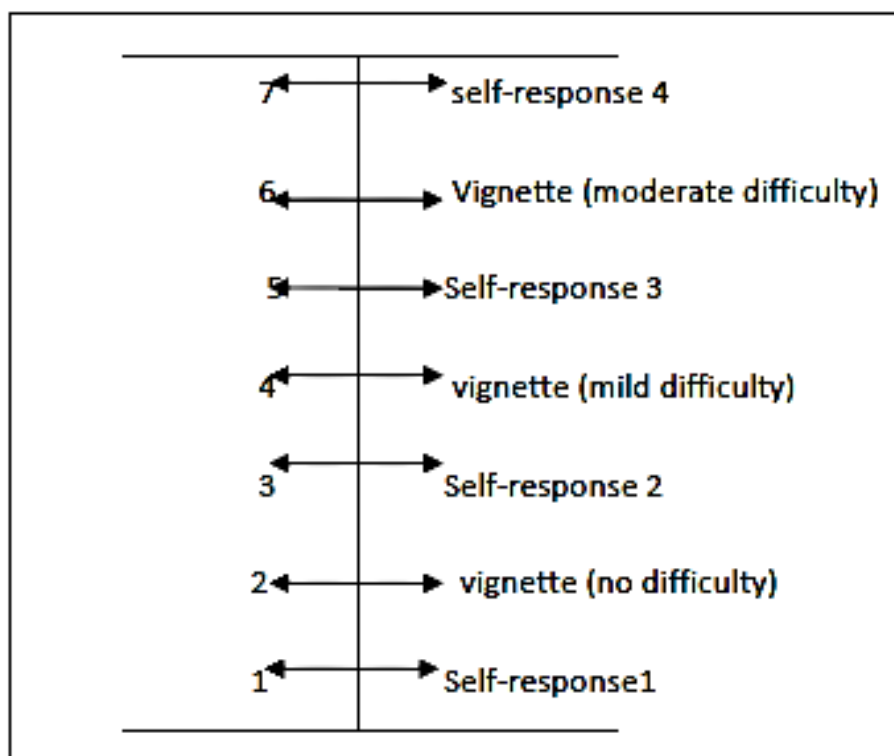
Figures 4.3:4 and 4.3:5 present the relative ranking of the mobility domain. Figure 4.3:4 presents the relative rankings of participants with one or two distinct responses to the anchoring vignettes. Figure 4.3:5 on the other hand presents the relative rankings of the survey participants with more than two vignette responses. Figure 4.3:4 illustrates that close to 60% of survey participants with one or two distinct vignette responses assessed their functioning difficulty to be less than that of the vignette with no functional difficulty. Figure 4.3:6, on the other hand illustrates that only 10% of the survey participants with more than two distinct vignette responses assessed their functioning difficulty to be less than that of the vignette with no functioning difficulty. Figures 4.3:4 and 4.3:5 further demonstrate that more male participants assessed themselves to have no functioning difficulty compared to the female participants. In other words, male participants perceived themselves to function better than female participants.

Figure 4.3:5 Relative rankings of participants with one or two distinct vignette responses

Censored Ordered Probit Allocation (Mobility)
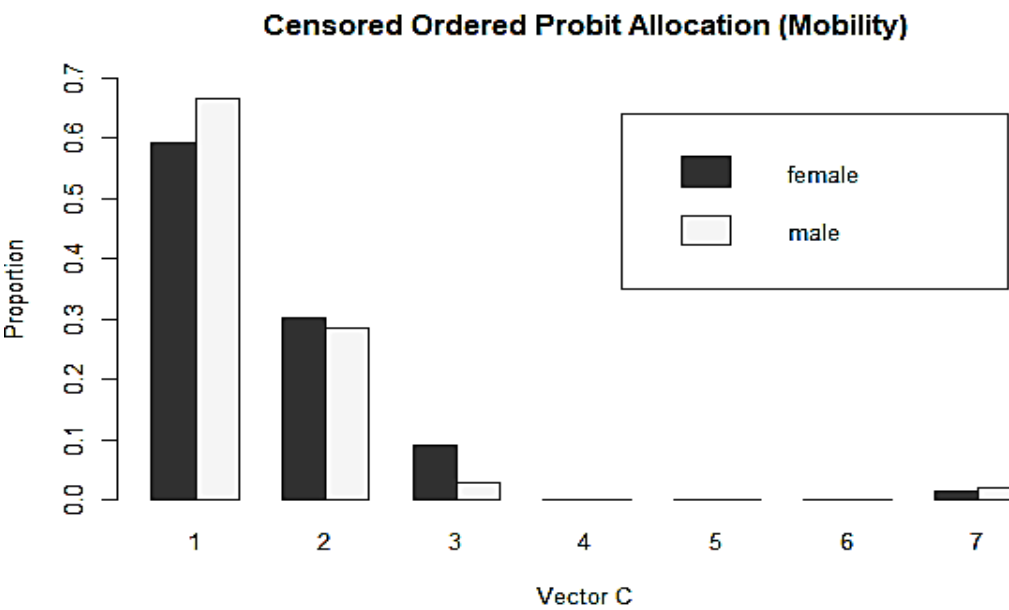
Figure 4.3:6 Relative rankings of participants with more than two distinct vignette responses

Censored Ordered Probit Allocation (Mobility)
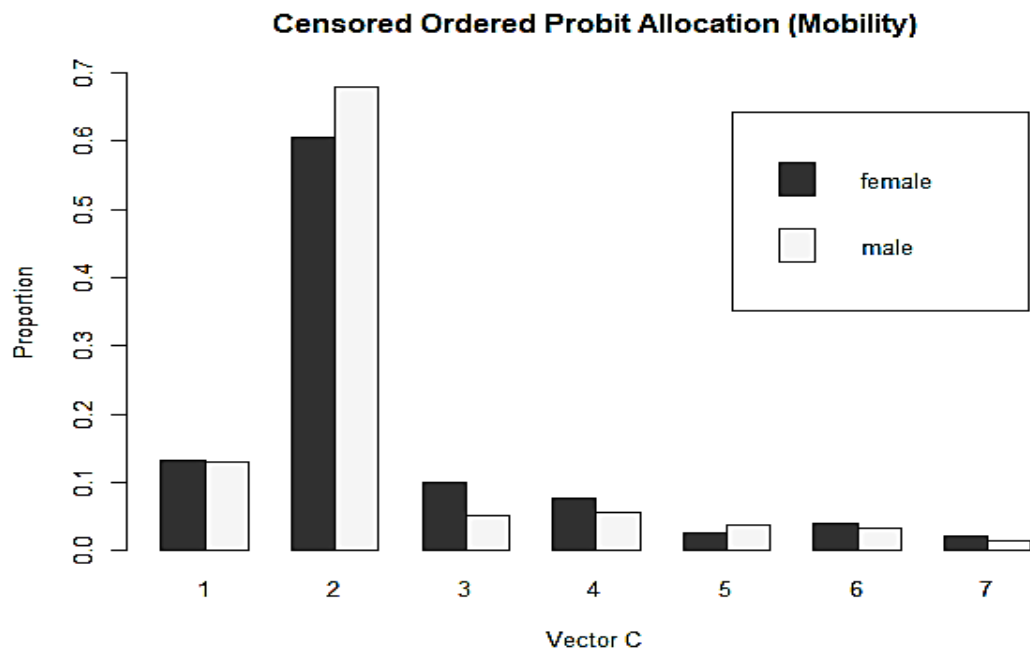
Apart from comparing the participants with one or two distinct vignette responses and those with more than two distinct vignette responses, this study also presents a comparison of the relative ranking of the participants in the four health domains of mobility, pain and discomfort, affect and cognition. Figure 4.3:6 presents four bar charts of male and female participant's allocation of the vector C of four health domains; Mobility, Pain and discomfort, Affect and Cognition. The x-axis represents minimum to maximum values of vector C, which were created from consistent ordering of anchoring vignettes in relation to ordinal responses of the self-assessment question as explained in the analysis section 4.2.4.3. The results indicate that most of the survey participants rated their health status to be better than that of the anchoring vignettes as illustrated in figure 4.3:6. Among the four health domains more than half of the survey participants rated their functioning difficulty to be equivalent to the vignette with no functioning difficulty and only a few participants rated their functioning in relation to the vignettes with mild or moderate levels of functioning difficulty.

The bar charts on mobility on the top-left illustrate that more than 60% (C=2) of female participants rated their functioning to be equal to that of the vignette with no mobility limitation compared to 55% of male participants. The bar chart further illustrates that close to 20% (C=1) of both male and female participants rated themselves as having less difficulty in mobility compared to the vignette with no functional difficulty.

With regards to pain and discomfort, the bar charts on the top-right illustrate that equal proportions (40%) (C=2) of male and female participants assessed themselves as having had no experience of pain or discomfort in the 30 days before the survey. However, a significant proportion (10%) of both male and female participants rated themselves as experiencing pain and discomfort that was more than the vignette with moderate pain and discomfort (C=7).

The light bars on the bottom-left bar chart for Affect indicate that more male participants ranked themselves in relation to the vignette with no affect problems, compared to female participants (53% relative to 49% respectively). Concerning the higher functioning levels, the affect bars indicate that more female participants rated their experience of affect or depression problems to be equivalent or more than the vignette with moderate problems, compared to male participants (C=6 & C=7). In terms of Cognition difficulty the bar charts on the bottom right illustrate that a significant proportion of male participants rated their cognition difficulty to be less than that of the vignette with no cognition difficulty, compared to female participants (C=1). More female participants, on the other hand, rated their cognition difficulty to be in higher-level categories including mild and moderate difficulty compared to male participants (C=4, C=6 & C=7).

Figure 4.3:7 Relative rankings of the four health domains (Mobility, Pain and Discomfort, Affect and Cognition) among those with more than two vignette responses
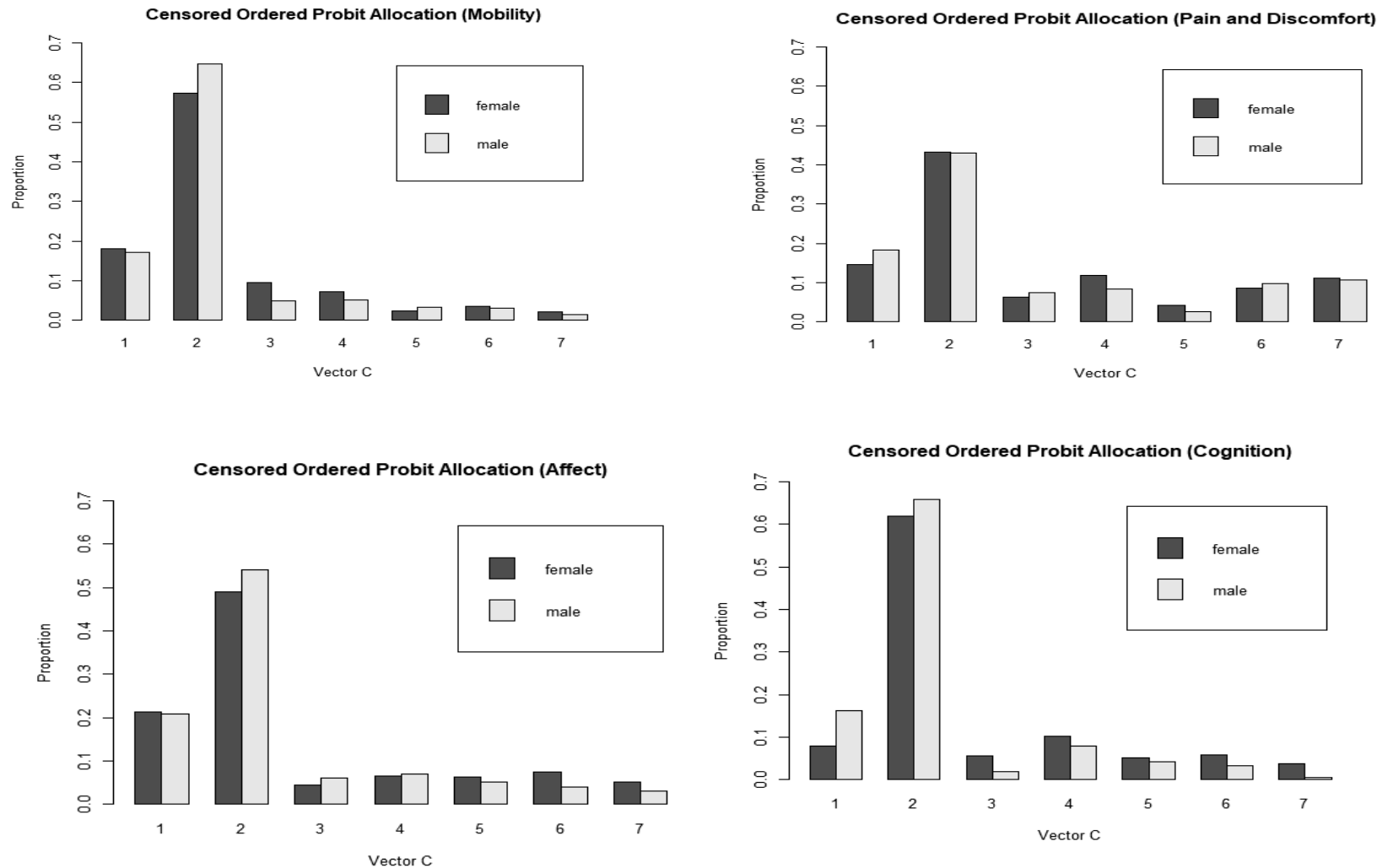
4.3.4   Results obtained from CHOPIT analysis

This section presents results obtained from the CHOPIT model, which models ordinal responses based on the assumption that there are variations in response category cut-off points, due to differences in understanding and use of the ordinal responses, by the survey participants. The CHOPIT results for each domain have been compared to the Ordered Probit model (which does not take into account the shift in cut-off points) to demonstrate the effectiveness of reporting heterogeneity.

<u>**Self-reported mobility**</u>

Table 4.3:4 presents the estimated regression coefficients of the socio-demographic variables on self-reported mobility before and after correcting for shifts in category cut-off points. The regression coefficients for the Ordered Probit model in the table indicate that, presence of an impairment, age of a participant and wealth index or economic status, are significantly associated with the reporting of mobility difficulty. With regards to impairments the regression results indicate that survey participants with impairments reported higher levels of mobility difficulty compared to participants with no impairments (β=0.819, p<0.05). A unit increase in age also increased the ordered log-odds of reporting mobility difficulty by 0.019. An increase in wealth or economic status on the other hand lowered the ordered log-odds of reporting mobility difficulty by -0.115 whilst holding the other variables in the model constant. Table 4.3:4 further indicates that place of residence, sex of a participants and the number of years spent in school are not significantly associated with the reporting of mobility difficulty.

Comparing the coefficients of the Ordered Probit and the CHOPIT model, the results in the tables indicate that there is no significant difference in the reporting of mobility difficulty before and after correcting for shifts in category cut-off points. For example, place of residence continue to be non-significantly associated with the reporting of mobility difficulty even after correcting for shifts in category cut-off points. Sex of the respondent also remains non-significantly associated with the reporting of mobility difficulty even though it changes its signs from a negative coefficient to a positive coefficient in the CHOPIT model.

The effect of correcting for shifts in category cut-off points or the difference in regression coefficients between the Ordered Probit and the CHOPIT model can be explained by the predictors of threshold variation that have been given by the CHOPIT model in table 4.3:4. In table 4.3:4, the threshold levels explain how the participants with various socio-demographic characteristics differentiated the response categories for the anchoring vignettes. For example,

threshold 1, indicates how the participants differentiated the categories for none and mild difficulty. Among persons with and without impairments, the estimate (β=-0.208) indicates that persons with impairments had a lower threshold for differentiating between "none" and "mild", as a result they were more likely to choose mild to describe an anchoring vignette than persons without impairments. This explains why the regression coefficient of the CHOPIT model reduced in value compared to the Ordered Probit model (β=0.660 from β=0.819). The threshold predictor for the sex variable (β=0.121) also helps explain why the sign of the regression coefficient for the CHOPIT model changed. The threshold predictor of β=0.121 indicates that male participants had a high ability to differentiate between none and mild difficulty, as a result they were more likely to choose "none" over "mild" when describing the anchoring vignettes.

For the higher level threshold coefficients , their interpretation depends on the previous threshold and involves exponentiation of the coefficients (Grol-Prokopczyk, Freese and Hauser, 2011). Therefore, to interpret the coefficients beyond the first threshold, the coefficients are presented visually in the form of mean estimated thresholds. Figure 4.3:8 presents the mean estimated intercategory thresholds for the impairment (top) and sex (bottom) variable. The figure for the impairment variable indicates that for all the 4 intercategory threshold, persons with impairment had lower thresholds compared to persons without impairments. That is to say, persons with impairments were more likely to choose the upper level in describing the mobility difficulty of the anchoring vignettes compared to persons without impairments. With regards to the sex variables, the bar chart for the sex variable indicates that women had lower threshold levels compared to men in the none/mild and moderate/severe intercategories and the same threshold as men in the mild/moderate and severe/extreme intercategories. This means that women were more likely to choose the upper response categories compared to men when describing the mobility difficulty of the anchoring vignettes.

Table 4.3:4 estimated regression coefficients of socio-demographic variables on self-reported mobility before and after correcting for shifts in category cut-off points

Socio-demographic Variable	_Before Correction_ (Ordered Probit Model)		_After Correction_ (CHOPIT model)	
	β	P-value	β	P-value
Presence of an impairment vs no impairment	0.819	<0.001	0.660	0.001
Rural vs Urban	-0.052	0.668	-0.200	0.137
Age (in years)	0.019	<0.001	0.017	<0.001
Male vs Female	-0.097	0.276	0.024	0.804
Years of Schooling	-0.008	0.529	-0.021	0.116
Wealth index	-0.115	0.001	-0.132	0.001
Threshold 1 (None-Mild)				
Presence of an impairment vs no impairment			-0.208	0.066
Rural vs Urban			-0.134	0.032
Age (in years)			-0.004	0.018
Male vs Female			0.121	0.011
Years of Schooling			-0.014	0.024
Wealth index			-0.016	0.402
Constant	0.978		1.017	<0.001
Threshold 2 (Mild-Moderate)				
Presence of an impairment vs no impairment			0.058	0.691
Rural vs Urban			-0.117	0.170
Age (in years)			0.004	0.115
Male vs Female			-0.019	0.779
Years of Schooling			0.006	0.505
Wealth index			-0.042	0.126
Constant	1.730		-0.409	0.004
Threshold 3 (Moderate-Severe)				
Presence of an impairment vs no impairment			0.005	0.972
Rural vs Urban			-0.258	0.001
Age (in years)			0.006	0.009
Male vs Female			0.043	0.499
Years of Schooling			0.001	0.925
Wealth index			0.059	0.023
Constant	2.128		-0.750	<0.001
Threshold 4 (Severe-Extreme)				
Presence of an impairment vs no impairment			-0.024	0.805
Rural vs Urban			0.064	0.269
Age (in years)			0.000	0.759
Male vs Female			-0.107	0.010
Years of Schooling			0.006	0.282
Wealth index			0.032	0.051

Constant	3.134	0.072	0.505
Vignettes			
θ1		-0.045	0.838
θ2		1.387	<0.001
θ3		2.102	<0.001
θ4		2.539	<0.001
θ5		3.442	<0.001

Figure 4.3:8 Mean estimated intercategory thresholds, by impairment (top) and sex of the participant (bottom)
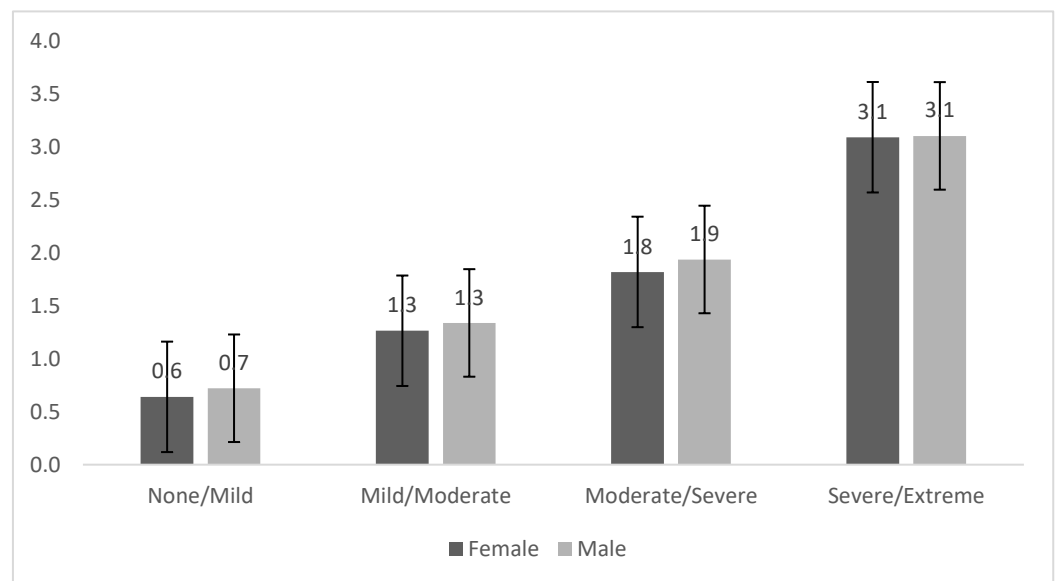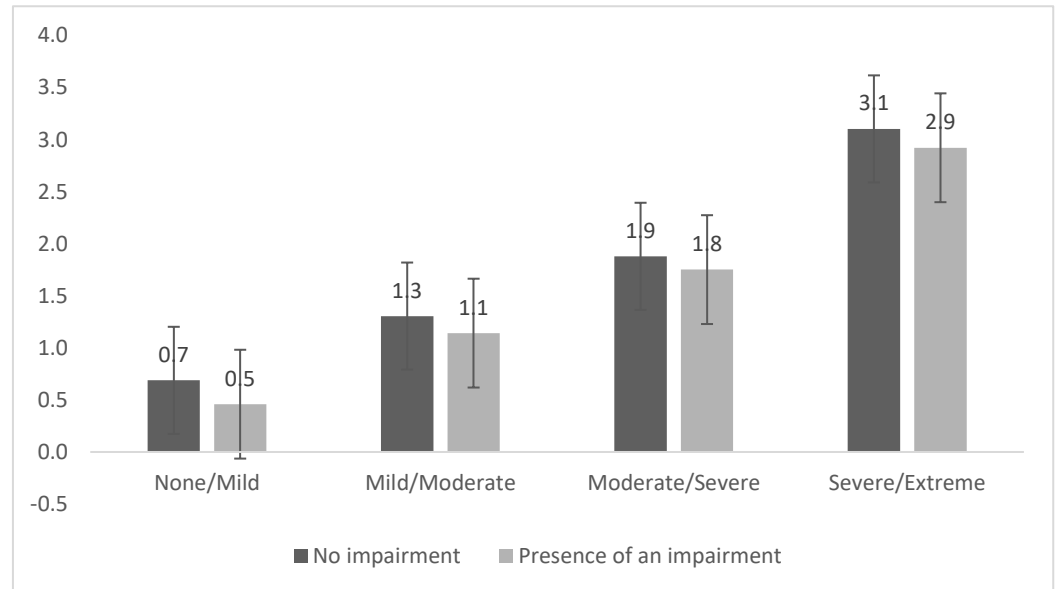
For the remaining health domains, the results only focus on the regression coefficients of the Ordered Probit and CHOPIT model and not the predictors for the threshold variation. CHOPIT models with predictors for the threshold variation are presented in Appendix B (tables 4.1 to 4.7). CHOPIT models with predictors for the threshold variations have not been presented here, to focus the discussion on the effectiveness of reporting heterogeneity.

Self-reported affect (depression)

Table 4.3:5 compares the results obtained from analysing the self-reporting of affect or depression with socio-demographic variables before and after correcting for shifts in category cut-off point. The results indicate that presence of an impairment, older age and wealth status are significantly associated with a greater severity in depression in the Ordered Probit model. The associations between impairment, wealth status and reporting of affect remain statistically significant after correcting for shifts in category cut-off points in the CHOPIT model. Age on the other hand becomes non-significant when corrected for shifts in category cut-off points. The non-significant association could be explained by the threshold variation between the young and older participants. The predictor for the threshold variation for age indicates that old people had a lower threshold for differentiating the none response and mild response, when describing affect vignettes, as a result they were more likely to choose mild over none difficulty.

Table 4.3:5 estimated regression coefficients of socio-demographic variables on self-reported affect (depression) before and after correcting for shifts in category cut-off points

Socio-demographic variables	*Before correction* (Ordered Probit Model)		*After Correction* (CHOPIT Model)	
	β	P-value	β	P-value
Presence of an impairment vs no impairment	0.572	0.001	0.587	0.001
Rural vs urban	-0.050	0.661	-0.137	0.251
Age (in years)	0.007	0.010	0.005	0.070
Male vs Female	-0.130	0.117	-0.065	0.450
Years of schooling	0.013	0.253	0.006	0.586
Wealth index	-0.094	0.004	-0.102	0.003

Self-reported pain and discomfort

In addition to mobility difficulty and affect, the study also analysed the self-reporting of pain and discomfort. The results in table 4.3:6 indicate that presence of an impairment, older age and wealth status are significantly associated with the reporting of severe pain and discomfort problems in the Ordered Probit model. These associations remain statistically significant after correcting for shifts in category cut-off points in the CHOPIT model. For example, presence of an impairment is associated with a 0.825 log-odds of reporting experiences of pain and discomfort at the 95% level of significance with an associated p-value of $p<0.05$ in the Ordered Probit model.. However, just like in the self-reporting of mobility difficulty and affect, place of residence, sex of the participant and number of years spent in school continue to be not significantly associated with the reporting of pain and discomfort even if corrected for shifts in category cut-off points.

Table 4.3:6 estimated regression coefficients of socio-demographic variables on self-reported pain and   discomfort before and after correcting for shifts in category cut-off points

Socio-demographic variables	Before correction (Ordered Probit Model)		After Correction (CHOPIT Model)	
	β	P-value	β	P-value
Presence of an impairment vs no impairment	0.825	<0.001	0.805	<0.001
Rural vs urban	0.135	0.220	0.117	0.317
Age (in years)	0.012	<0.001	0.010	<0.001
Male vs Female	-0.005	0.947	-0.001	0.987
Years of schooling	-0.004	0.672	-0.011	0.306
Wealth index	-0.064	0.023	-0.061	0.040

Self-reported Cognition

Concerning the self-reporting of cognition or difficulties in concentration or remembering things, table 4.3:7 presents the results obtained from the Ordered Probit and the CHOPIT models. The results in the Ordered Probit model indicate that presence of an impairment, age of the participant and sex of the participant are significantly associated with the self-reporting of cognition problems. For example, participants with impairments have a higher log-odds ($β= 0.576, p<0.05$) of reporting cognition problems compared to persons without impairments.   Male participants on the other hand have a lower log-odds ($β=-0.298$) of reporting cognition problems compared to female participants. When corrected for shifts in category cut-off points the CHOPIT results in table 4.3:7 indicate that presence of an impairment, age of the participant and sex of the participant continue to be significantly associated with the reporting of cognition problems. Place of residence, number of years spent in school and wealth status on the other hand remain not significantly associated with the self-reporting of cognition problems.

Table 4.3:7 estimated regression coefficients of socio-demographic variables on self-reported Cognition before and after correcting shifts in category cut-off points

Socio-demographic variables	Before correction (Ordered Probit Model)		After Correction (CHOPIT Model)	
	β	P-value	β	P-value
Presence of an impairment vs no impairment	0.576	<0.001	0.490	0.002
Rural vs urban	0.003	0.982	0.028	0.833
Age (in years)	0.010	<0.001	0.008	0.003
Male vs Female	-0.298	0.001	-0.317	0.001
Years of schooling	-0.021	0.090	-0.020	0.118
Wealth index	-0.040	0.222	-0.060	0.082

Self-reporting of personal relationships

Further to the analysis of self-reporting of cognition, this study also assessed the self-reporting of difficulties in maintaining personal relationships. The comparative analysis of the Ordered Probit and the CHOPIT models is presented in table 4.3:8. The Ordered Probit results of the reporting of personal relationships in the table, indicates that presence of an impairment, place of residence and age of the participants are significantly associated with the self-reporting of difficulties in maintaining personal relationships. However, when corrected for shifts in category cut-off points, the CHOPIT model results in the table indicate that place of residence is no longer significantly associated with the reporting of difficulties in maintaining personal relationships. Nonetheless, presence of an impairment and age of participant continue to be significantly associated with the reporting of difficulties in maintaining personal relationships. Sex of the participant, number of years spent in school and wealth index on the other hand, are not significantly associated with the reporting of difficulties in maintaining personal relationships.

Table 4.3:8 estimated regression coefficients of socio-demographic variables on self-reported difficulty in Personal Relationships before and after correcting for shifts in category cut-off points

Socio-demographic variables	*Before correction* (Ordered Probit Model)		*After Correction* (CHOPIT Model)	
	β	P-value	β	P-value
Presence of an impairment (vs no impairment)	0.404	0.022	0.447	0.019
Rural (vs urban)	0.289	0.043	0.265	0.079
Age (in years)	0.012	<0.000	0.009	0.003
Male(vs Female)	0.095	0.304	0.125	0.205
Years of schooling	0.004	0.732	0.000	0.973
Wealth index	-0.027	0.439	-0.022	0.564

Self-reported difficulties in sleep and energy

With regards to the reporting of difficulties with sleep and energy, the Ordered Probit Model in table 4.3:9, indicates that this aspect is only significantly associated with the age of the participant. A unit increase in age increases the ordered log-odds of reporting difficulties in sleep and energy by 0.012. The Ordered Probit Model in table 4.3:9, further indicates that presence of an impairment, place of residence, sex of the participant, number of years spent in school and wealth status are not significantly associated with the reporting of difficulties in sleep and energy. When corrected for shifts in category cut-off points, the CHOPIT model result in table 4.3:9, indicate that only the age of the participant is significantly associated with the reporting of difficulties in sleep and energy. The rest of the independent variables continue not to be significantly associated with the reporting of difficulties in sleep and energy.

Table 4.3:9 estimated regression coefficients of socio-demographic variables on self-reported sleep and energy before and after correcting for shifts in category cut-off points

	Before correction		After Correction	
	(Ordered Probit Model)		(CHOPIT Model)	
Socio-demographic variables	**β**	**P-value**	**β**	**P-value**
Presence of an impairment (vs no impairment)	0.170	0.313	0.192	0.292
Rural (vs urban)	-0.150	0.225	-0.229	0.086
Age (in years)	0.012	<0.001	0.010	<0.001
Male(vs Female)	-0.071	0.407	-0.009	0.924
Years of schooling	-0.004	0.755	-0.019	0.128
Wealth index	-0.032	0.312	-0.031	0.371

Self-reported difficulty in vision

In addition to the reporting of difficulties in sleep and energy, this study also analysed the reporting of vision or problems with seeing objects or people at a distance. The Ordered Probit model results presented in table 4.3:10, indicate that presence of an impairment and age of the participants are the only socio-demographic variables that are significantly associated with the reporting of vision problems. Presence of an impairment and age of the participant continue to be significantly associated with the reporting of vision problems even when corrected for shifts in category cut-off points in the CHOPIT model. The CHOPIT model results also indicate that number of years spent in school is also significantly associated with the reporting of vision problems. A unit increase in years spent in school reduces the log-odds ($\beta=-0.032$, $p<0.05$) of reporting difficulties in seeing objects or people at a distance. This significant association between schooling years and the reporting of vision problems has not been observed in the Ordered Probit model, this then reflects the effectiveness of incorporating the reporting heterogeneity when analysing self-reported disability.

Table 4.3:10 estimated regression coefficients of socio-demographic variables on self-reported vision before and after correcting for shift in category cut-off points

|	*Before correction*		*After Correction*	
	(Ordered Probit Model)		**(CHOPIT Model)**	
Socio-demographic variables	**β**	**P-value**	**β**	**P-value**
Presence of an impairment (vs no impairment)	0.568	<0.001	0.546	0.002
Rural (vs urban)	-0.177	0.228	-0.283	0.069
Age (in years)	0.021	<0.001	0.019	<0.001
Male(vs Female)	-0.052	0.597	0.043	0.678
Years of schooling	-0.014	0.300	-0.032	0.027
Wealth index	-0.062	0.086	-0.059	0.121

Self-reported difficulties in self-care

Further to difficulties with seeing objects or people at a distance, this study also examined the reporting of self-care. Self-care relates to the reporting of difficulties in washing or dressing oneself. The Ordered Probit model results presented in table 4.3:11, indicate that presence of an impairment; age and sex of the participant are significantly associated with the reporting of difficulties with self-care. With regards to the sex of the participant, men have a significantly lower ordered log-odds (β=-0.229, p<0.05) of reporting difficulties in self-care compared to women, when all the other variables in the model are held constant. Table 4.3:11, further indicates that when corrected for shifts in category cut-off points, presence of an impairment, age and sex of the participant continue to be significantly associated with the reporting of difficulties in self-care.

Table 4.3:11 estimated regression coefficients of socio-demographic variables on self-reported self-care before and after correcting for shifts in category cut-off points

	Before correction		After Correction	
	(Ordered Probit Model)		(CHOPIT Model)	
Socio-demographic variables	β	P-value	β	P-value
Presence of an impairment (vs no impairment)	0.560	<0.001	0.538	<0.001
Rural (vs urban)	0.162	0.278	0.261	0.091
Age (in years)	0.016	<0.001	0.015	<0.001
Male(vs Female)	-0.229	0.018	-0.262	0.009
Years of schooling	-0.005	0.710	0.008	0.590
Wealth index	-0.041	0.253	-0.055	0.143

 To sum up, this chapter aimed to examine the self-reported measurement of disability in Malawi. To attain this objective, the chapter used descriptive statistics, vignette equivalence, relative ranking and Compound Hierarchical Ordered Probit modelling techniques. The results obtained from these techniques have demonstrated that:

- Of all the sampled population, 6 % had impairments, and that a higher proportion of the female participants (6%) had impairments compared to the male participants (5%).

- Concerning the reporting of functional limitations, this study has found that persons with impairments reported higher levels of functional limitations such as moderate and severe limitations compared to persons without impairments.

- This study has also found that both young people aged between 18 and 35 and older people aged 36 and above rated the functioning difficulties of the anchoring vignettes at the same level.

- The relative ranking results obtained in this study have also shown that more than 60% of the survey participants ranked their health state as being equivalent to the vignette with no functioning difficulty, in all the eight health domains.

- With regards to the self-reporting of difficulties in mobility, affect, pain and discomfort, cognition, personal relationships, sleep and energy , vision and self-care, the Probit model results in this study have shown that presence of an impairment significantly contributes to the reporting of all the health domains except the reporting of difficulties in self-care. For example, people who have an impairment have an increased ordered log-odds of reporting mobility difficulties of 82% compared to those with no impairment.

- Age on the other hand is significantly associated with the reporting of difficulties in all the eight health domains prior to the adjusting for vignette ranking. A unit increase in age has been found to be positively associated with the reporting of difficulties in mobility, personal relationships, self-care and seeing objects or people at a distance.

- With regards to the adjustment for reporting heterogeneity using anchoring vignettes in the CHOPIT models, this study has found that anchoring vignettes did not significantly improve the reporting of functioning difficulties in mobility, pain and discomfort, cognition, sleep and energy, and self-care. For example, in the reporting of mobility difficulties, the Probit model results indicated that presence of an impairment, age and the wealth status of a participant are positively associated with the reporting of mobility difficulties. After adjusting for reporting heterogeneity, the CHOPIT model indicated that there were no significant difference in the coefficient values of the CHOPIT and Probit results and that presence of an impairment, age and wealth status remained to be significantly associated with the reporting of mobility difficulty.

- Nonetheless, use of anchoring vignettes significantly adjusted the reporting of depression problems, personal relationships and vision. With regards to depression problems, use of anchoring vignettes has changed the effect of age from being significantly associated with the reporting of depression problems to not being significantly associated with the reporting of depression problems.

- The use of anchoring vignettes has also adjusted the influence of number of years spend in school from being non-significantly associated with the reporting of vision problems in the Probit model to being significantly associated with the reporting of vision problems in the CHOPIT model.

4.4   Discussion

A bivariate analysis of functional limitations in the domains of mobility, affect, sleep and energy, pain and discomfort, cognition, vision, personal relationships and self-care among survey participants with and without an impairment, has demonstrated that participants with an impairment reported higher levels of functional limitations in all the eight health domains compared to those without an impairment. These study findings support Hermann et al (2001) and Gure et al (2009) findings in the United States of America. Hermann et al (2001) in their study of patients with cervical spine disorders, found impairments to be highly correlated to functional measures with a correlation coefficient of r=0.82. According to Hermann et al, impairments are positively correlated to functional limitations because persons with cervical spine disorders lack

muscle strength and spinal motion needed   to carry out their daily activities (Hermann and Reese, 2001). Gure et al (2009), also found participants with vascular dementia to have significant limitations in bathing, dressing, eating and walking compared to participants with non-vascular dementia.

With regards to this study, persons with impairments included persons in wheelchairs, persons using canes, crutches, walkers, persons with paralysis, or an amputation, persons with vision and hearing problems and persons with mental problems.   Research on persons using wheelchairs in the United States has indicated that most persons who use wheelchairs experience "upper extremity pain that interferes with essential activities of daily living", (Curtis *et al.*, 1999). Persons with mental health in the Netherland and the United States on the other hand have been found to have the worst physical, social and role functioning, that includes sustaining concentration, interacting with others, responding to negative feedback and they experience greater bodily pain, compared to persons with no chronic conditions (Wells *et al.*, 1989; Bijl and Ravelli, 2000). The functional limitations findings in the Netherland and the United States support the current study's where persons with impairments reported more functional limitations compared to persons without an impairment.

In addition to the reported functional limitations, this study has also found that both young and old people evaluated the functioning of the hypothetical persons at the same level. In other words, young people and old people gave lower ranks to vignettes that were describing lower levels of functioning difficulties and higher ranks to vignettes that were describing higher levels of functioning difficulties. These study findings correspond to those found by Damacena et al (2005) in Brazil. Damacena et al (2005) found that there were minimal variations in the evaluation of the pain experiences of the hypothetical persons between survey participants with a range of different socio-economic backgrounds. According to Damacena et al (2005) the minimal variation in vignette response among the study participants with different levels of education could relate to the poor comprehension of the vignettes by the participants. With regards to these study, the similarity in the response values assigned to the anchoring vignettes could relate to the minimal variation in educational status since more than 70% of the participants had less than primary education. Thus their comprehension of the level of difficulty expressed in the vignettes was almost the same.

This study has also found that more than 50% of the survey participants ranked themselves in relation to the vignette with no functional limitation rather than the vignettes with mild, moderate or severe functional limitations. These study findings correspond to Sen (2002) observations in Bihar India, where survey participants reported to have low rates of morbidity

even though they were living in a resource poor environment where there were limited medical and health facilities. Research on self-health perceptions has indicated that people who live in resource-poor environments often report being in good health, even though they have limited access to medical facilities, because they have less awareness of treatable conditions (Sen, 2002; King *et al.*, 2004). This means that they fail to distinguish between natural health states and ill-health states. Au et al (2014) has also noted that when people are assessing their own health, they consider their medical conditions and the psychosocial aspect of responding to the questions, which includes past experiences of health, vulnerability to illness, the impact of the ill health on their work or social activities, future health expectations and the reference group. All these health and psychosocial factors lead to inconsistencies in the rating of health of hypothetical persons and individual health (Au and Lorgelly, 2014).

With regards to Malawi, a majority of people live in poverty as measured by the total annual per capita consumption in food and non-food items such as health and transport (NSO, 2012). The 2010-2011 Malawi Integrated Household survey indicates that 50.7 % of people in Malawi live below the poverty line, and have little or no access to clean water and health facilities (NSO, 2012). As much as the majority of the population live in poor conditions, it is likely that they have adjusted to their poor health condition such that they take their health condition as the norm. This could explain why more than 60% of the sampled participants ranked themselves as having no functional limitations. Apart from adapting to the local environment, consideration of the impact of the health states on subsistence farming could have also influenced the mean responses to the self-health questions, since close to 85% of the sample were from rural areas (NSO, 2016b;2017) . Thus if the ill health was not impacting on their daily farming activities, such as land preparation or harvesting, the participants were more likely to have ranked themselves as having no functional limitations.

 With regards to the correction of shifts in category cut off points, this study has found that old age and presence of an impairment remains statistically associated with the reporting of severe difficulties in mobility, pain and discomfort, vision, cognition, sleep and energy, personal relationships and self-care. Wealth status on the other hand is only negatively associated with the reporting of mobility, affect, pain and discomfort. The findings on the continued association between old age and sleep and energy after correcting for shifts in category cut-off points, correspond to the study finding of Tareque et al (2016) in Japan. In their study on whether adjustment for reporting heterogeneity is necessary in sleep disorders, Tareque et al (2016), found older age and presence of multiple morbidities to remain significantly associated with

sleep-disorders, after correcting for shifts in cut-off points. According to Tareque et al (2016), these findings signify the impact of old age and co-morbidities on sleep and energy related problems. With regards to the current study findings, the continued significant association of old age and sleep and energy and the continued positive regression coefficients, not only signifies the effects of age but also the need to prioritise age in the formulation of policies and programmes on health provision.

The lack of a significant effect of anchoring vignettes in calibrating the reporting heterogeneity in mobility, pain and discomfort, cognition, personal relationships, sleep and energy and self-care in the CHOPIT outputs, support the study findings of Grol-Prokopczy et al (2015) and Damacena et al (2005). Grol-Prokopczy et al (2015) found the anchoring vignettes used in the Global AGEing and Adult Health (SAGE) survey of China, Ghana, India, Mexico, Russia and South Africa and those used in the World Health Survey of Brazil, France, Netherlands and the United Kingdom, not to affectively enhance the reporting heterogeneity of functional difficulties in mobility, pain, depression, social relationships, distance vision, sleep, memory and self-care (Grol-Prokopczyk *et al.*, 2015). According to Grol-Prokopczy et al (2015), anchoring vignettes failed to calibrate the difference in use of the response categories of the study participants because the participants in the different demographic groups appeared to understand the vignette texts as representing different levels of health. With regards to the present study, the non-significant effectiveness of the anchoring vignettes in calibrating the reporting heterogeneity in the CHOPIT models could relate to the socio-economic status of the sampled population. Even though the sampled population were from different ethnic backgrounds such as Chewa and Tumbuka, a majority of the participants had less than primary education (70%) and were from the rural areas (86%) where the living conditions and health service utilization are almost the similar.   The similarity in the background characteristics of education and place of residence could have led the study participants to have the similar perception of health or health expectations, even though they were of different ages and different ethnic backgrounds. The similarity in individual health may have contributed to small variations in the cut-off points of the self-assessment response categories. The small variations in the response category cut-off points of the self-assessment questions rendered the use of anchoring vignettes as being non-effective since the aim of anchoring vignettes is to calibrate the difference in category cut-off points. The minimal difference in the cut-off points help explain why there were no significant difference in the regression coefficients of the Probit and CHOPIT model.

 Nevertheless, the use of anchoring vignettes in the CHOPIT model of affect (depression) personal relationships and vison, help calibrate the reporting of functional difficulties among people of different ages, places of residence and years of schooling. The calibration effect of the anchoring

vignettes on place of residence correspond to the results obtained by king et al (2004) in their study of reported political efficacy between China and Mexico. In this study of political efficacy King et al (2004) used anchoring vignettes to enhance the validity of the reported political efficacy. The results of this study indicated that before correcting for shift in category cut-off points, Mexicans had more political efficacy or freedom compared to the Chinese, but after correcting for the shift in category cut-off points the results indicated that it was the Chinese who had more political efficacy and not the Mexicans. The change in the direction of political efficacy demonstrates the effectiveness of using anchoring vignettes to correct for interpersonal incompatibility. With regards to this study, the change in the significant effect of age from positive association to non-significant association demonstrates in the reporting of problems with depression illustrates that the problems of depression may not only be experienced by old people , young people may also be experiencing depressive disorders. This necessitates the need for including both young and old people when providing services for affect or depression disorders.

4.5   Conclusion

In conclusion, this chapter aimed at assessing the self-reported measurement of disability in Malawi, through the use of anchoring vignettes and Compound Hierarchical Ordered Probit modelling. The assessment has shown that persons with impairment reported higher levels of functional limitations in all the eight health domains (mobility, affect, and cognition, self-care, vision, pain and discomfort, personal relationships and sleep and energy) compared to persons without an impairment. This study has found that old age and presence of an impairment remain significantly associated with severe limitations in functioning in all the eight health domains, even after correcting for shifts in category cut-off points. This findings on impairment and age suggest that persons with impairments and older people report higher levels of functioning limitations than young people and those without an impairment.

Apart from the reporting of functional limitations the results obtained in this chapter have also shown that most people in the country evaluate their health status or health functioning in relation to their experiences and health expectation and not according to other people's health status such as those described in the anchoring vignettes. This implies that people do not use the response scale of the anchoring vignettes or third parties in the same way that they use for their self-evaluation. Therefore, when collecting information on the disabling condition of a particular health conditions caution has to be taken when interpreting responses to hypothetical stories.

Further to the use of the response categories, this study has also shown that the use of anchoring vignettes in the CHOPIT model did not significantly improve the reporting outcomes in all the health domains. The anchoring vignettes only changed the reporting heterogeneity of affect, personal relationships and vision. These findings suggests that it is not in all cases that anchoring vignettes will be needed to calibrate the reporting heterogeneity. The reporting of functional limitations in some other health domains may not be significantly affected by the socio-demographic characteristics of the study participants. Therefore, when designing surveys it is imperative that piloting of the anchoring vignettes should be conducted to assess its effectiveness in calibrating the reporting heterogeneity. The piloting of the vignettes could help reduce the cost of collecting data that may not improve the study outcomes.

5   Chapter 5: Investigating the conceptual understanding of disability in Malawi

5.1   Introduction

Having observed that the 2003 Malawi World Health survey participants were using their health expectations to evaluate their functioning status, this study further explored the conceptual understanding of disability in Malawi. This chapter discusses the conceptual understanding of disability in Malawi. The rationale for the discussions stems from the understanding that the conceptualization of disability is socially described (Groce, 1999; Loeb, Eide and Mont, 2008). Understanding how disability is conceived is also crucial to its measurement, formulation, and implementation and the monitoring of programs aimed at providing services to persons with disabilities. Exploring people's conceptual understanding of disability is also important because, not only is it the basis that people use to identify themselves as having a disability, but it is also the basis which community members use for implementing programmes and policies at the community level (Groce, 2006; Katsui, 2008) . This means that if disability is not clearly conceptualized by a society, it is difficult for persons with disabilities to be well considered in social development and development programmes within which their needs are supported. In this study, several sections of the society were approached to provide their viewpoints on how disability is conceived. These research participants come from Chinamwali and Jali1 areas in Zomba and Bangwe and Daniel Village in Blantyre. This chapter presents results that shed some light on how the community understands disability, but before presenting the results, the chapter discusses the method used to collect and analyse the information.

5.2   Methods and data used for understanding the conceptualization of disability in Malawi

To examine the conceptual understanding of disability in Malawi, this study used focus group discussions. Focus group discussions were used to provide an insight into the dynamics of cultural norms and attitudes towards the conceptualization of disability. Participants in the focus group discussions were men and women aged 18 years and above. This population sub-group was chosen based on the assumption that they have had an encounter with a person with a disabling condition or that they may have accessed SRH services. Persons with disabilities were not

specifically targeted for the focus group discussion even though they are the ones who experience the disabling condition and are in a better position to provide the best possible solution for addressing their sexual and reproductive health needs (Oliver, 2004). Persons with disabilities were not targeted because most disability studies in sub-Saharan Africa have reported that one of the main challenges experienced by persons with disabilities when accessing sexual and reproductive health services is the negative attitude or misconceptions of health service providers and the community members (Smith *et al.*, 2004; Ahumuza *et al.*, 2014; Munthali *et al.*, 2017). This study, therefore aimed to understand the root cause of the misconceptions or negative attitude of the community members by investigating their understanding of disability. It was envisaged that the information given by the community members will assists in understanding the basis for the misconception and provide approaches that can be used to address the misconceptions that are being held by the community members.

 The focus group discussions were conducted in Zomba (Chinamwali and Jali 1) and Blantyre (Bangwe and Daniel Village) districts. These districts were chosen because of their ease of access and cost-effectiveness in terms of transport and accommodation. In each sampled area, focus group discussions were conducted separately for each gender. To explore community members' conceptual understanding of disability, participants in the focus group discussions were asked questions that have been presented in box 4.2.1 below;

Box 5.2:1 Conceptual understanding of disability and attitudes to the SRH behaviours of persons with disabilities

Now I would like to know more about this area. What are the long-term illnesses common in this area?

1. Let's discuss the meaning of these disabling conditions (long-term illnesses) a little bit more. How do you understand the term disability?

Probes: a) Their understanding of disability, different types of disability (visible or invisible)

How do you know about disability?

Probe: Who provides you with information about disability? Did you make up your own mind or do others decide it? Do you consider people with albinism as having a disability?

2. Now I would like to discuss some delicate matters related to sexual and reproductive health. What are your views on people with disabilities bearing children?

Probe: Why? What are your views on persons with disabilities having sex, using contraceptive methods? How would you react if someone with a visible disability came into your shop to buy condoms?

From the above questions, the participants gave answers that included;

> "Disability can be defined in a number of ways including failure to give birth (infertility), hearing problems, vision problems, and also having a short leg or arm, failing to speak (dumbness-lutaka)", (Male FGD, Daniel village, Blantyre)

> "The dumb can be noticed when one fails to respond verbally and instead uses signs to speak. In addition, the deaf requires one to speak on top of their voice if they are to hear what one is saying or may require one to use signs for them to understand what is being communicated to them", (Male, FGD, Chinamwali, Zomba)

The researcher then developed eight thematic areas using the Nvivo 11.4 (a statistical package for analysing qualitative data). Nvivo11.4 was also used to code the responses from all the eight focus group discussions. The eight thematic areas are: behaviour, the cause of disability, mental illness, invisible disability, visible disability, religion, social expectation and albinism. The eight themes were presented to the research team to verify if they were a true reflection of what has been gathered from the focus group discussions. After a thorough discussion, the research team decided to regroup the proposed eight themes into six thematic areas due to the similarities of

some of the proposed themes. The six agreed themes are; (i) disability as visual physical feature; (ii) understanding disability in relation to societal expectations; (iii) understanding disability as mental health; (iv) understanding disability in relation to activity limitation; (v)understanding disability based on cause of illness or disabling condition; (vi) albinism as a form of disability.

The thematic areas were not grouped into urban or rural and male and female even though the data was corrected based on gender and place of residence, because the ideas coming from the various focus groups were almost similar. For example on the conceptual understanding of disability, a focus group of women described disability as "a persons who has a body part that does not function normally like other body parts" (Female FGD, Chinamwali, Zomba). Men on the other hand described disability as "having an abnormally short let that makes one fail to walk properly", (Male, FGD, Chinamwali, Zomba). The similarity in the responses given towards the conceptual understanding of disability and other areas of the discussion led to the decision of focusing on the main issues rather than disaggregating the thematic areas or the results by gender or place of residence.

Table 5.2.1 below presents a summary of the themes that were developed after the thematic analysis of the focus group discussions.

Table 5.2:1 Table explaining the development of themes from focus group discussions

Responses to the conceptual understanding of disability	Proposed theme	Agreed theme
Sometimes to know that this person has a disability, you see that his other leg is bigger than the other	Visible disability	Disability as a visual physical feature
Disability is when you differ from what God created you from the beginning.	Religion	
A person who is not giving birth has a disability because they are not doing what they are expected to be doing	Social expectation	Understanding disability in relation to societal expectation
An invisible disability whereby one speaks anyhow without considering the people that are around him	Invisible disability	
We can identify one who is mentally disabled through one's action and behaviours, a mentally disabled person doesn't think in an normal way	Mental illness	Disability as mental health
If a person is just crying on his own you can tell that this has a disability, his head is not working properly	Behaviour	
The dumb can be noticed when one fails to respond verbally and instead uses signs to speak	Behaviour	Disability in relation to activity limitation
Some people have an impaired leg which makes them fail to walk properly	Behaviour	
There are three forms of disability, some people are inborn, there is also disability which comes due to illness for instance stroke, and there is another form of illness which comes as one gets old	cause of disability	Disability based on the cause of illness or disabling condition
People with albinism are not persons with disabilities, they are normal people. There is no reason to discriminate these people because they are normal only that we differ in skin colour.	Albinism	Albinism as a form of disability

5.3 Results of the Focus group discussions

5.3.1 Characteristics of Focus group respondents

To explore the conceptual understanding of disability in Malawi, 59 participants from Zomba and Blantyre took part in the focus group discussions as shown in table 5.3:1. The table indicates that a high proportion of male participants were aged above 55, with a percent distribution of 33.3% and a median age of 42. Women on the other hand, were mostly aged between 35 and 44 with a percent distribution of 31.3% and a median age of 44. In terms of education, the table illustrates that a majority of the participants (62.7%) had primary education, with women constituting 71.9% of the participants with primary education compared to men (51.9%). The table further

demonstrates that more than half of the participants were from the rural areas (55.9%) compared to urban areas (44.1%). In terms of gender, most women were from the rural areas (62.5%) compared to male participants (48.1%). With regards to marital status the table indicates that more than half of the participants (57%) were married. Relating marital status to the sex of the participant, the table demonstrates that more than four-fifths (88.9%) of men were married compared to a third of the women (31.3%). Half of the women in the sampled population were divorced whereas none of the men were.

Table 5.3:1 Distribution of men and women in focus group discussions

Background Characteristics	*Men*	*Women*	*Men and Women*	*Number*
Median age	42	44	44	
Age group				
20-34	22.2	21.9	22.0	13
35-44	29.6	31.3	30.5	18
45-54	14.8	18.8	17.0	10
55+	33.3	28.1	30.5	18
Total	100	100	100	59
Level of education				
None	14.8	9.4	11.9	7
Primary	51.9	71.9	62.7	37
Secondary	33.3	18.8	25.4	15
Total	100	100	100	59
Place of Residence				
Urban	51.9	37.5	44.1	26
Rural	48.2	62.5	55.9	33
Total	100	100	100	59
District				
Zomba	51.85	50	50.85	30
Blantyre	48.15	50	49.15	29
Total	100	100	100	59
Marital status				
Married	88.9	31.3	57.6	34
Divorced	0.0	50.0	27.1	16
Widowed	3.7	18.8	11.9	7
Never married	7.4	0.0	3.4	2
Total	100	100	100	
Total number	27	32		59

5.3.2 Community perspectives on disability in Malawi

There is no single definition of disability in Malawi. Community members in the sampled population of Zomba and Blantyre understand disability in relation to a person's visual physical features, societal expectations, functional limitation and cause of illness or disabling condition. With regards to physical features of a person, the community members compare the features of a person and those of the rest of the members of the society. If a person has physical features that are different from the rest of the population such as a paralysed leg, that person is classified as having a disability. Disability is also interpreted in relation to societal expectations, in such a way that community members have different expectations for a child, an adolescent, a single adult and a married couple. For example, children are expected to assist their parents with household chores such as sweeping, and cleaning dishes. If a child is failing to carry out such activities due to a disabling condition (e.g. mental illness), parents may suspect that such a child has a disability (Nelson *et al.*, 2017). The cause of an illness or disabling problem can also lead to a person being classified as having a disability. For example, if a person suffers a mental illness from natural causes such as Malaria, such a person may be classified as having a disability, but if the cause of the mental illness is drugs such as marijuana, that person is not classified as a person with a disability.

To provide a detailed understanding of disability in Malawi, the following sections discuss how disability is understood in relation to visual physical features, societal expectations, activity limitation, causes of a disabling condition and albinism.

5.3.2.1 Theme 1: Disability as a visual physical feature

Community members in both urban and rural areas of Zomba and Blantyre described disability in relation to what they perceive as the normal physical features of a person. They view a person as a normal human being if the person looks similar to them or has the same body structures as themselves or the rest of the members of the society. So if a person has a visible body structure that is different from them, they classify that person as having a disability as illustrated in the following excerpts;

> "Disability means abnormality that exists in people and makes them naturally different from others", Male FGD, Chinamwali, Zomba

> "Sometimes to know that this person has a disability, you see that one of his legs is bigger than the other. You know that this person has a disability", Female FGD, Daniel Village, Blantyre

"You are able to see with your own eyes that this one is not the same as we ought to be

born. He is not equal with others. When he draws near to you, you are aware and able to

say this is not the way we ought to be", Male, FGD, Bangwe, Blantyre.

Disability, in this case, is understood based on the differences in the outward physical

appearance, from what all other people are supposed to look like in the community. It is a

physical anomaly confirmed by physical observation.

The perception of disability in relation to physical outlook is also influenced by a community

member's religious beliefs. As discussed in the research design chapter, a majority of people in

both Zomba and Blantyre are Christians or Muslims, who believe that God created man and that

man is an image of God. To be an image of God, means that you do not have any deformity such

as a mutilated face or a hunchback. Therefore, when community members see someone whose

body structure is different from what their religious belief teaches, they label that person as a

person with a disability.

"Disability is when you differ from what God created you from the beginning. For

example, if the leg has to be straight and then you have a paralysed leg. This is what we

call disability", Male FGD, Bangwe, Blantyre.

5.3.2.2   Theme 2: Understanding disability in relation to societal expectations

Societal expectations also influence peoples' understanding of disability in Malawi, apart from

religious beliefs. Married couples in the country are expected to have children, for personal,

economic as well as socio-cultural reasons (de Kok, 2008; Kendall and Anglewicz, 2016). Children

are of benefit to married couples because they are a source of income and security in their old

age due to the non-availability of a social security system in the Country (de Kok, 2008). If a

couple fails to have children when they are expected to, community members then perceive such

people as a person with a disability, as is noted in this view;

 "An example can be that which my friend has just said of infertility. The couple may be

married for several years but fail to have a child. This is an invisible form of disability, they

may try all means for the woman to conceive but nothing successful comes out", Male

FGD, Jali1, Zomba.

In addition to the social expectation of bearing children, there are some behaviours and practices

that are not socially expected and when a person does them, she or he is classified as a person

with disability. For example, an adult crying in public when there is no funeral, being stubborn or

speaking words that do not make sense and eating rotten food from rubbish bins. These inordinate behaviours and practices make community members think that such a person has a disability in some way. That is the person does not have a proper sense of thinking or have a right mind.

> "You can easily see that this person has a disability. If a person is just crying on his own, you can tell that this person has a disability, his head is not working properly", Male FGD, Bangwe, Blantyre.

> "Sometimes persons with disabilities are very stubborn you tell him or her that this is not good you'll see him or her continuing doing the same thing. This is a sign of a disability. Sometimes the mental problem may start while he or she is at school. Sometimes you can be chatting with a person, but all of a sudden, he'll start talking about different things. He can go to school but the way he responds to the situation you'll realise that something is wrong with this person. He or she is sick in the head", Female FGD, Daniel Village, Blantyre.

The above two explanations illustrate how social expectations towards the members of the society help community members identify people with mental illnesses.

5.3.2.3   Theme 3: Mental illness as a disability

Mental health, according to the World Health Organization is a "state of well-being in which an individual realizes his or her potential, can cope with the normal stresses of life, can work productively and fruitfully and is able to make a contribution to his or her community", (World Health Organization, 2017). Mental illness, on the other hand, refers to a range of mental health conditions or disorders that may affect a person's mood, thinking and behaviour (Link *et al.*, 2004). Mental disorders may include depression, anxiety disorders, schizophrenia, eating disorders and addictive behaviours. Globally, mental illness accounts for 32.4% of Years Lived with Disability (YLDs) and 13.0% of Disability Adjusted Life-Years (DALYs) (Vigo, Thornicroft and Atun, 2016). In Malawi, it is estimated that the prevalence of common mental disorders among primary health care patients ranges between 20% and 28.8% (Udedi, 2016).

 Mental illnesses or disorders have no definite cause, but research on mental illness has shown that genetic, biological, psychological and environmental factors may contribute to the onset of mental illness (Link *et al.*, 1999; Hyman, 2000; Schmidt, 2007). Research on the genetics of mental illness has shown that multiple genes act in concert with non-genetic factors such as psychological trauma to produce a risk of mental disorders (Hyman, 2000). A chemical imbalance in the brain also known as neurotransmitters have also been found to cause schizophrenia and major

depression (Link *et al.*, 1999). Mental illness has also been found to be caused by psychological factors such as stress, severe psychological trauma and emotional, physical or sexual abuse (Schmidt, 2007).

Apart from genetic and biological factors, mental illness is also believed to be caused by supernatural causes such as witchcraft and bad behaviours (Razali, Khan and Hasanah, 1996; Schnittker, Freese and Powell, 2000). For example, a study on the cause of mental illness among Malay patients, indicated that 53% of mental patients attributed their illness to supernatural agents such as witchcraft and possession of evil spirits (Razali, Khan and Hasanah, 1996). This belief in supernatural causes was higher among the patients who had consulted traditional healers (bomohs) compared to those who had not consulted them. In the United States, black people are more likely to support the suggestion that mental illness is caused by God's will or a bad addiction such as drug abuse, than white people (Schnittker, Freese and Powell, 2000).

With regards to causes of mental illness in Malawi, traditional beliefs, psychological and medical factors are also believed to cause mental illnesses (Maclachlan, Nyirenda and Nyando, 1995; Crabb *et al.*, 2012). In terms of traditional beliefs, both societal members and people who suffer from mental illnesses believe that mental illness is caused by witchcraft, being possessed by evil spirits and punishment from God. For example, a study on the attributes for admission to Zomba mental hospital by Maclachlan et al (1995), found 32 out of 103 patients mentioned traditional attributes as the cause of their mental illness. One of the traditional attribute relates to being bewitched by workmates or a relative because the person works hard and is married to a beautiful woman (Maclachlan, Nyirenda and Nyando, 1995). With regards to medical causes, a cross-sectional study on attitudes towards mental illness at Queen Elizabeth Central Hospital by Crabb et al (2012), reports that 92.8% of patients and carers attending both mental and non-mental health-related clinics mentioned brain diseases such as Malaria and traumatic events and shocks as causing mental illness.

 Basing on the understanding that mental illness significantly contributes to years lived with a disability, and that there is a lot of misconception and stigma associated with mental illnesses, participants in the focus group discussions were asked if they regarded mental illness as a disability. Most of the participants in both rural and urban areas of Zomba and Blantyre districts said that they do regard mental illness as another form of disability. They further explained that they identify people with mental illness through their actions or behaviour.

"When one is mentally disturbed is also a disability because he or she does not know what he is doing, he is abnormal", Male FGD, Chinamwali, Zomba.

"The easiest way to know that this person is normal in the head is what he or she is doing. An example is a mental illness, which affects the brain; you will know that this person is not good with his or her head because of how he or she is speaking. This is a disability which we cannot see", Female FGD, Daniel Village, Blantyre.

However, not all mentally ill persons are regarded by the community members as having a disability . According to the participants, only people who were born with a mental illness or whose mental illness was caused by diseases such as Malaria are regarded as persons with disabilities. People, whose mental illness has been caused by drug abuse, such as the taking of marijuana or the use of sorcery to get rich, are not regarded as persons with disabilities. These types of mental illnesses are regarded as carelessness.

"We can consider them as having a disability or not depending on how the mental illness came about. There are some forms of mental illness, which come about due to the use of charms. One may wish to get rich through the use of charms and these charms may be unsuccessful, we consider such mental illness as resulting from one's carelessness", Male FGD, Jali1, Zomba.

From this quotation, it can be deduced that the community members regard not all mental illnesses as a disability. Thus, despite mental illness being identified through a person's behaviour, the cause of the mental illness also helps in determining the disability status of an individual.

5.3.2.4   Theme 4: Understanding disability in relation to activity limitation

Disability in Malawi is also understood in relation to a person's functioning status. People are labelled as having a disability if they fail to engage in daily activities such as hearing, walking, speaking or engaging in a conversation with fellow community members. Community members expect that when a person has been spoken to, the person will respond, but if the person fails to respond or to ask questions, they suspect that that person has a disabling condition.

"We have another disability whereby a person is not able to speak words and to understand the other person. He cannot speak sound words. He looks normal and we know that he sees us and yet for him to ask a question for help, he cannot. Even when we ask him to do something, he does not understand. We know by this, that this one has a disability", Male FGD, Bangwe, Blantyre.

Apart from speaking, people who have difficulties in walking are also perceived by the community members as having a disability. The main economic activity in the sampled populations is farming or fishing, therefore, a person is expected to be able to walk to get to the farm or the lake to work, so if he or she is failing to walk that person is perceived as having a disability.

> "We have another disability whereby one does not walk normally, rather he crawls, this is also what we call disability", Male FGD, Daniel Village, Blantyre.

In this case, disability is conceived in relation to how each member of the society travels from his or her homes to the farm or the workplace.

5.3.2.5   Theme 5: Understanding disability based on the cause of illness or disabling condition

Participants in the focus group discussions also conceptualized disability in relation to the cause of the disabling condition. According to them, there are various forms of disability, some disabilities are inborn (that is a person is born with a disability), some disabilities are caused by illnesses such as leprosy, a stroke or cancer and other disabilities occur as one gets old. Therefore, the cause of the disability determines whether a person will be labelled as having a disability or not. For example, if a person in his or her old age suffers from a stroke, which results in a paralysed leg, then that person may be regarded as a person with a disability.

> "Disability can be considered in three forms, that which is inborn, there is also a disability which comes due to illness for instance stroke, and there is another form of disability which comes as one gets old" Male FGD, Jali1, Zomba.

> "Sometimes those suffering from cancer are amputated to prevent cancer from spreading that is also a disability", Female FGD, Daniel Village, Blantyre.

 Even though community members conceptualise disability depending on the cause of the disabling conditions, some mothers with children with disabilities fail to understand the cause of disability experienced by their children as expressed in the following narration;

> "I was told that my mother was a healthy looking girl, but she met her fate one night when she was 12 while she was asleep, when she found out that she could not walk. She called her mother to escort her outside because she is failing to walk, the legs are paralysed. My grandmother was furious because she thought she was joking. Later on, she realized that it wasn't a joke, but she tried to make her stand, but she could not manage, all the lower side from the hip was paralysed. In the morning, they took her to

the hospital but it did not work. They took her for prayers during Bonkies time but it

didn't work. This time she is a person with a disability. She cannot walk instead she just

crawls", Female FGD, Daniel Village, Blantyre.

This failure to understand the cause of disability led one female participant with a child with a

disability to describe disability as a problem that a person encounters in life before he or she is

born or after his or her birth. Mothers of children with disabilities fail to understand the cause of

disability because their children have been born without any health condition or deformity, and

even when they go to the hospital, the hospital personnel fail to explain the cause of their child's

illness to them.

5.3.2.6   Theme 6: Albinism as a form of disability

Albinism is a rare genetic condition that affects the pigmentation of the retina, hair and skin

(Wan, 2003). People with albinism have little or no eye skin, or hair pigment and are often

burdened with sensitive skin and poor vision (Braathen and Ingstad, 2006). The unconventional

physical appearance and the visual impairment have caused people with albinism to experience

discrimination and stigma, problems that are often experienced by persons with disabilities.

The stigma and discrimination faced by persons with albinism also stem from the lack of

understanding of the cause of albinism. In developed countries such as North America people

with albinism are portrayed as oddities and villains (Wan, 2003). There is also a tradition in

Hollywood where people with albinism are equated to evil or aliens. In South America, lack of

understanding of disability, make San Blas Indians of Panama to regard people with albinism as

moon-children, because "they avoid the bright sunlight of the day and conduct their daily

activities in subdued light (Wan, 2003). In sub-Saharan Africa, including Tanzania, South Africa and

Zimbabwe, there are also myths and misconceptions regarding people with albinism (Baker *et al.*,

2010; Brocco, 2015). For instance in Tanzania, there is a misconception that the blood, skin and

hair of people with albinism have magical powers that can make one become rich (Brocco, 2015).

This misconception has led to the brutal killings of albinos ever-since 2007.

 The literature on albinism in Malawi has also shown that people in Malawi have limited

understanding of the cause of albinism; as a result there are a number of myths and

misconceptions surrounding the condition. The most common myth in Malawi is that " if a

pregnant woman looks at a person with albinism, she will have a child with albinism ", (Braathen

and Ingstad, 2006). To prevent this situation, pregnant women are advised to spit on the ground

when they look at a person with albinism. Women who have albino children also believe that

they gave birth to an albino child because they themselves had an illness called Mwanamphepo

(Braathen and Ingstad, 2006; Lynch, Lund and Massah, 2014). Mwanamphepo is a skin disease,

which causes illnesses to new-born babies if the mother has the disease during childbirth. People in Malawi also hold the belief that albinism is caused by the will of God. Thus, they cannot explain a mystery. Others also hold the belief that albinos do not die like other people, they just disappear (Lynch, Lund and Massah, 2014). The killings of people with albinism in Tanzania has also made some Malawians believe that people with albinism can be killed and used as magic to get rich. This misconception of getting rich from albino skin, has made people with albinism live in fear, and has led to the killing of albinos in Malawi. For instance, it has been reported that since 2014, 18 people with albinism have been killed and five people have disappeared without a trace (Amnesty International, 2016).

It is this knowledge concerning the stigma and discrimination faced by persons with albinism and the recent killings of albinos in Tanzania and Malawi, which led the researcher to ask the study participants about their perceptions of people with albinism, particularly in relation to disability. In most of the focus group discussions, participants said that they do not view persons with albinism as persons with disabilities. According to them, people with albinism are normal people, because they are born like community members and born from parents whose skin colour is similar to that of the community members. They said that the skin pigment of persons with albinism is God's creation, they cannot explain a mystery. Concerning disability, the community members perceive people with albinisms as not having a disability because they do not have visible impairments or fail to fulfil social expectations such as having children.

Despite persons with albinism being perceived as normal people, the community members did acknowledge that persons with albinism face discrimination when it comes to employment, particularly MASAF jobs. MASAF, stand for Malawi Social Action Fund, it is a public works programme that is funded by the World Bank (Kishindo, 2000). This programme aims at creating employment opportunities for rural Malawians through intensive labour such as rehabilitation and maintenance of economic infrastructures such as rural roads (Kishindo, 2000; Dulani, 2003) . The Public Works Division manages MASAF jobs, but at the community levels, it is the village heads or community -chairpersons that identify persons eligible for these employment opportunities. It is at this level that persons with albinism are discriminated against.

In addition to being discriminated against employment, community members also mentioned that persons with albinism sometimes face difficulties finding sexual or marriage partners. This difficulty in finding a marriage partner is more pronounced in men than in women. When it comes to dating, men with dark skin find it hard to ask women with albinism for a date, instead they ask their male friends to ask the albino woman for a date for them. In terms of marriage, men who

marry women with albinism are happy just like those who marry non-albino women as narrated by the following participant;

> "We sometimes admire women with albinism and wish to marry them. I have an example from my friend who married a woman with albinism saying these women are like any other normal woman and do manage what all other married women do in marriage", Male FGD, Jali1, Zomba.

Even though women with albinism do not face difficulties in getting married, men with albinism do face difficulties when it comes to marriage, particularly if they come from a poor household as explained by this village head who is also an albino;

> "Ah as a Chief…, I have a friend, my friend who looks just like me, like an albino. My friend is facing challenges in finding a partner to marry", Male FGD, Daniel Village, Blantyre.

The above excerpts from a participant with albinism demonstrates the livid experiences of persons with albinism. Thus, even though the other members of the community reported that they do not perceived persons with albinism as persons with disabilities and that they are comfortable with marrying them, persons with albinism are experiencing marital challenges that are similar to those of persons with disabilities. The excerpts, thus demonstrates the benefits of collecting sexual and reproductive health information from persons with disabilities since they are the ones who experience the challenges of accessing sexual and reproductive health services. Thus they are more likely to direct researchers on the best possible ways of addressing their unmet need of sexual and reproductive health services. The excerpts also reflects the global principle of persons with disabilities which states that" Nothing about us without us" (WHO and UNFPA, 2009). Thus we cannot address the sexual and reproductive health challenges of persons with albinism without involving them in the discussion. Nonetheless, the collection of the sexual and reproductive health information from persons with albinism or disability was beyond the scope of this study. Thus further research on the conceptualization of disability and utilization of sexual and reproductive health services has to be conducted where persons with albinism will be the target population.

Apart from marriage formation, people with albinism are also burdened with a skin, which gets burnt when exposed to the sun. The community members suspect that the burning that people with albino skin suffer, is due to lack of use of skin lotions, which albinos receive at the health facility, and not wearing hats that protect them from direct sunlight. Thus there are a number of critical issues that needs to be addressed in relation to the sexual and reproductive health needs of persons with albinism.

5.3.3   Community perspective on the SRH of persons with disabilities

With regards to sexual and reproductive health services, disabilities studies have indicated that societal attitudes influence persons with disabilities' access and utilization of SRH services (Munthali, Mvula and Ali, 2004; Smith *et al.*, 2004; Groce, 2006). This study explored community member's perceptions towards the SRH behaviour of persons with disabilities. The community members were particularly asked to provide their views on persons with disabilities bearing children and accessing family planning services or using contraceptive methods. Perceptions on the SRH behaviour of persons with disabilities were sought from the community members because of the assumption that people's conceptual understanding of disability may influence the uptake of SRH services among persons with disabilities. For example, the 2006 report by the Federation of Disability Organization in Malawi (FEDOMA), reports that persons with disabilities in the country are assumed to be sexually inactive, and as a result they are denied access to reproductive health and HIV and AIDS information (FEDOMA, 2006). Mji et al (2008) also found that the negative attitude of nurses and other medical staff towards women with disabilities in Malawi, was discouraging pregnant women with disabilities from accessing delivery and post-natal services.

A thematic analysis of the information collected from rural and urban areas of Zomba and Blantyre districts indicates that there are both positive and negative attitudes towards the bearing of children by persons with disabilities. Community members who have a positive attitude towards persons with disabilities bearing children, argue that children are of benefit to persons with disabilities as they may assist them with household chores, or provide old age security. Others are of the view that it is a fulfilment of their human right. However, there are concerns about the care that persons with disabilities can provide for their children. To address this concern, the community members have suggested that persons with disabilities should only bear two or three children.

> "We understand that children are future leaders and having them means parents have someone to rely on when they get old. Persons with disabilities who get married should have children like any other couple because the children can relieve them from their challenges in near future. The same children can provide help and care for their parents with disabilities when they get educated and become responsible citizens", Female FGD, Jali 1, Zomba.

"They can have freedom of having children and they should have ways or source of making money like working or doing business so that they should be able to provide for the children", Male FGD, Bangwe, Blantyre.

"By saying 2 or 3 kids. I think that they can be able to support these kids", Male FGD, Bangwe, Blantyre.

The above excerpts demonstrate that community members understand the benefits of bearing children among persons with disabilities. Their only concern is the care that would be provided to the children of persons with disabilities.

With regards to the negative attitude towards persons with disabilities bearing children, the main concerns are the pregnancy complications that may arise from the different types of disabilities. There are also concerns about the care that parents with disabilities may to give to their children. The main concern relates to persons with epilepsy. The community members are worried that when an epileptic person is suffering an attack, that this may pose a risk to the child. For example, if epilepsy starts when they are washing clothes at the river, the child may be thrown into the river or thrown onto the fire when they are cooking. For some community members, particularly mothers of persons with disabilities, they just do not want their children or relatives with disabilities to bear children. Parents to persons with disabilities perceive their children or relatives with disabilities as a liability, so they do not want to have an extra burden of taking care of the children of persons with disabilities.

"In this regard, we need to take into consideration the form of disability that one has. If a disability can lead to the death of the mother during delivery or pregnancy, then we can say it is not good for such woman to give birth….. The danger lies at giving birth. …….. Some forms of disability can pose serious health risks to a woman during pregnancy or delivery", Male FGD, Chinamwali, Zomba.

"For example, my child is always using a wheelchair, all the legs are very rigid, such that she can hardly open them, so how do you think that person will deliver a baby at the labour ward. Maybe if we take the mother of this one… she gave birth to her without any problems. But with my child the situation is worse, she cannot bear a child, because the degree of disability is very high. She cannot even take care of the child, which means that the responsibility will be on me, or even she can die while giving birth to a child", Female FGD, Daniel Village, Blantyre.

The two narratives above, provide an insight into the fears and misconceptions that community members have towards the child-bearing of persons with disabilities. People have the misconception that disability increases the risk of complications during pregnancy or delivery. Parents with children with severe disability are also afraid of their children dying during child birth and of having to take care of the new-born child. These misconceptions and fears may hinder persons with disabilities from not only giving birth but also accessing SRH services.

In addition to childbearing, focus group participants were also asked to provide their views on persons with disabilities accessing family planning or contraceptive methods. An analysis of their responses indicates that community members are of the view that persons with disabilities should access family planning methods such as condoms, to protect them from sexually transmitted infections and pregnancy. Persons with disabilities should also access family planning methods so that they can only have a small number of children for ease of management. However, not all community members have good intentions for allowing persons with disabilities to access family planning methods. Some community members would like persons with disabilities to access family planning methods so that they do not give birth, thus reducing the load that might be placed on the community member of taking care of children of relatives with disabilities.

> "Yes, I can sell them the condoms. I can do that with the intention of preventing them from having a child. They can go ahead and have sex since they also have sexual feelings but they should not have a child. They cannot manage to take care of the child", Male FGD, Jali 1, Zomba.

> "I think accessing contraceptive methods is the best thing for persons with disabilities, particularly those with mental illness because they cannot take care of their children. So they should access contraceptive methods especially sterilization", Female FGD, Daniel Village, Blantyre.

> "Yes, it is good that persons with disabilities should be using family planning methods so that they should not get pregnant and acquire sexually transmitted infections", ……., Male FGD, Daniel Village, Blantyre.

 The above excerpts, provides the reasons that community members have towards the use of contraceptive methods among persons with disabilities. The reasons indicate that persons with disabilities may be encouraged by community members to access SRH services.

To summarise the results section, with regards to the conceptual understanding of disability in Malawi, the study has found that disability in the two sampled districts is conceptualised in relation to

- A visual physical feature
- societal expectations
- mental illness
- activity limitation
- the cause of illness or disabling condition

The results have also shown that albinism is not perceived as a disability in the sampled populations.

With regards to childbearing and contraceptive use, the study has found that;

- There are both positive and negative attitudes towards the childbearing behaviour of persons with disabilities.
- Use of contraceptive methods among persons with disabilities is also positively and negatively perceived.

5.4   Discussion of the results obtained from the focus group discussions

This chapter aimed at exploring the conceptual understanding of disability in Malawi, by approaching some community members in Zomba and Blantyre districts. A thematic analysis of the focus group discussions with the community members has shown that disability in these communities is conceptualised in five different ways; as a visual physical feature, in relation to societal expectation, in relation to mental illness, as activity limitation and in relation to the cause of disability.

Disability is a concept that has evolved overtime, as witnessed by the continued development of the WHO international classification system and the various conceptual models of disability. As the concept of disability has been evolving, the issue of impairment (physical or mental characteristic) has continued to stand out. For example, in the 1980 WHO International Classification of Impairment, Disabilities and Handicaps (ICIDH), disability was conceptualised in relation to impairment (World Health Organization, 1980). The current, WHO International Classification of Functioning, Disability and Health (ICF), also incorporates the issue of an impairment (World Health Organization, 2001;2002). The impairment findings from this study , therefore demonstrates that the contribution of impairment in the conceptualization of disability is not only acknowledged by the global community but also the sampled communities in Malawi.

Literature on the conceptualization of disability as an impairment has shown that this conceptualization affects the estimation of the number of persons with disabilities. According to Palmer et al (2011), impairment measures of disability produce low estimates of persons with disabilities. The low estimate occurs due to its focus on severe cases of disabling conditions. This means that when disability is conceptualised as a visual physical feature, only those with visible impairments can identify themselves as having a disability during surveys and censuses. This in-turn affects disability estimates, because only those with severe or profound impairments are counted, and those with invisible impairments, such as intellectual disabilities, are excluded because the society does not perceive them as persons with disabilities.

Further to the conceptualization of disability as an impairment of visual physical feature, this study has found that disability is also perceived in relation to societal expectations. The finding on the conceptualization of disability in relation to societal expectations supports the assertion that the socio-cultural context of an individual influences the understanding of disability (Ingstad, 1995; Groce, 1999; World Health Organization, 2002; Katsui, 2008). For instance, Groce (1999) in her description of local concepts and beliefs about disability, has reported that societal expectation of adulthood in Polynesia, such as eloquence in public forums, is what classifies an individual as either having a disability or a person with no disability. The results obtained from this study therefore support this conceptualization, because the societal expectation of childbearing among married couples is what made community members in the sampled communities, consider childless couples to those having a disability.

The conceptualisation of disability in relation to societal expectations is important in disability studies, because it influences people's responses to disability questions thus affecting disability estimates. People's responses to disability questions are affected because people respond to disability questions relative to some unspoken cultural standards of what is considered normal functioning (Mont, 2007a; Loeb, Eide and Mont, 2008). Disability estimates on the other hand are affected, because some people may not self-identify as having a disabling condition, resulting in lower estimates of disability. For instance, a woman with high blood pressure, who has children and goes to the farm, is more likely not to identify herself as having a disabling condition, because she has all the elements intact that define a woman in her society. Therefore when collecting disability data for policy development or implementation, it is necessary to incorporate the socio-cultural context of the population under scrutiny.

The results obtained from the focus group discussions have also indicated that disability in these communities is understood in relation to mental illnesses. According to the World Health

Organization (WHO), mental illnesses or disorders comprise of schizophrenia, depression, intellectual disabilities and disorders due to drug abuse. However, the participants of this survey have said that they do not recognize mental illness, resulting from drug abuse and sorcery, as disabilities. The community member's perceptions are in contrast with the WHO propositions, but support the Chung (1998) and Leshner (1997) assertions that there is a wide gap between scientific facts and public perceptions about drug abuse. According to Leshner, Science teaches that drug abuse is a health problem that needs to be addressed by the health care systems (Leshner, 1997). The public, on the other hand, perceive drug-related problems as a social problem that needs to be handled with social solutions (Leshner, 1997; Chung, 1998). This difference in perception of drug abuse has implications in the health-seeking behaviours of individuals with mental illnesses, because of the minimal support available from the community members. Therefore, to improve utilization of health services by people with mental illnesses due to drugs, the public needs to be informed that mental illnesses due to drugs are also disabilities.

In addition to being understood in relation to a person's physical features and societal expectations, disability in the sampled populations was also perceived in relation to activity limitation. Perceiving disability as an activity limitation is important in SRH service provision studies, because it encourages health seeking behaviour (Larsson and Mattsson, 2001; Stahl and Patrick, 2011). For example, in a study on perceived functional limitation and health promotion during mid-life to late life, Stahl et al (2011) observed that adults who perceived themselves as having severe functional or activity limitation were more likely to seek professional medical assistance compared to adults who perceived themselves as having less functional limitation. In addition to increased health-seeking behaviour, research on the measurement of disability has also indicated that when disability is perceived as activity limitation it encompasses a wide range of disabling conditions rather than being viewed as an impairment (Mont, 2007b; WHO and World Bank Group, 2011).

With regards to albinism, findings from this study have demonstrated that community members in Zomba and Blantyre do not perceive persons with albinism as persons with disabilities, despite the conclusion drawn by Braathen et al (2006) that people with albinism in Malawi are considered as persons with disabilities. This difference in findings on perceptions about persons with albinism could be attributed to a change in socio-cultural belief systems. According to Groce (1999), when local cultural beliefs systems intersect with western ideas, they are interwoven and produce a hybrid traditional system that influences people's perceptions towards disability. For the case of Malawi, the recent killings of Albinos in the country which have prompted awareness campaigns on albinism could have contributed to the change in attitude towards people with albinism (Amnesty International, 2016). Therefore, the findings in this study, not only help in

understanding people's perception of albinism but also demonstrate the dynamic nature of socio-cultural beliefs on disability.

This study has further revealed that people in the sampled populations view the skin of people with albinism as a mystery supporting what Braathen et al (2006) found in their study of albinism in Malawi. According to Braathen et al (2006), people in Malawi have little knowledge of albinism. This limited knowledge of albinism makes the community members attach names of popular persons with albinism, as a way of describing persons with albinism. The names include, yellow man (a Jamaican Reggae artists) or Zigoma (a popular Malawian gospel artist with albinism). Therefore, a lack of understanding of albinism could also explain why people in the sampled populations regard persons with albinism as not having a disability.

 The different understandings of disability that have been observed in this study demonstrates that the community members in Malawi have a multidimensional perspective of disability. Disability is conceptualised as an abnormally from creation (e.g. one leg is bigger than the other), something which is contrary to the social norm (e.g. childlessness) an activity limitation (e.g. difficulties in walking), and as a mental illness. However, a number of models that are used in disability research including the medical and social models of disability conceptualise disability as unidimensional aspect. This practice of collapsing the concept of disability as a single entity in disability models may adversely affect the collection of disability data and the subsequent implementation of policies and programmes. For example, if disability is only perceived as a social problem, people who have impairments may not identify themselves as having a disabling condition, as a result, they may shy away from seeking health care services. If policies or programmes focus only on one dimension of disability, there may be difficulties in implementation, because of the differences in understanding of disability between the community members and the programme developers. Therefore, to ensure that disability inclusive SRH policies and programmes are implemented, there is a need to conceptualise disability as a multidimensional concept.

The study findings where disability is perceived as a visual physical feature, fulfilment of societal norms, as mental illness, activity limitations and cause of disability correspond to the WHO ICF framework conceptualization of disability. The WHO ICF framework conceptualize disability as "dysfunctioning in one of the three interlinked levels of impairments in body function or structure, activity limitations, or participation restrictions and as the result of an interaction between a health condition and contextual factors", (Mactaggart *et al.*, 2016). The similarity in the conceptualization of disability between the Zomba and Blantyre community members and the

WHO ICF framework supports the assertion that the ICF framework is a universal classification of disability and health. The similarity in the conceptualizations also validates the credibility of the ICF framework as a conceptual basis for the measurement of disability in population censuses and surveys.

5.5 Conclusion

In conclusion, this chapter aimed to understand the conceptualisation of disability in Malawi, through a selection of a few communities in Zomba and Blantyre districts. The viewpoints of the selected communities were collected through focus group discussions. A thematic analysis of the focus group discussions has indicated that disability in the sampled populations is understood in five different ways. Disability is conceptualised based on the visual physical features of the person, conformity to societal expectations such as bearing children when married, ability to carry out daily activities such as the ability to engage in a conversation, mental illness and cause of an illness.

The different ways of understanding disability by the community members may influence the estimation of persons with disabilities and the implementation of policies and programmes for health service provision. Estimation of the number of persons with disabilities may be affected because persons with disabling conditions that do not fall within these five areas may easily identify themselves as not having a disability, thus reducing the proportion of persons with disabilities. Therefore, when developing survey or census tools that aim at measuring disability or estimating the number of persons with disabilities, it is imperative that all the five dimensional aspect of disability perceived by the community members are incorporated. The incorporation of the community members understanding of disability will assist in the complete coverage of all types of disabilities existing in the communities. The conceptual understanding of disability by the community members should also be incorporated during the development and implementation of sexual and reproductive health policies and programmes for effective implementations and reaching the target population.

This study has also shown that people with albinism in Zomba and Blantyre areas are not perceived as persons with disabilities. This is in contrast to what was found in an earlier study by Braathen et al (2006). The difference in study findings between this study and that of Braathen et al (2006) could be due to the research designs in the two research studies or a change in socio-cultural attitude towards disability over time. Braathen et al used in-depth interviews where the conclusion were drawn from individual opinions, whilst this study used focus group discussions where the conclusion are drawn from group opinions. Therefore, to comprehensively ascertain people's attitude towards persons with albinism, a quantitative study should be conducted to

obtain opinions of a representative sample, so that a definitive conclusion can be drawn. The quantitative study should randomly sample persons with albinism, their immediate family members and community members who have no experience with albinism. This will help in drawing conclusion from multiple perspectives.

6 Chapter 6: Data deficiencies in disability measurement

6.1 Introduction

The need to provide adequate sexual and reproductive health services to marginalised populations (people with disabilities, slum populations, street children and orphans) in sub-Saharan Africa necessitates the availability of reliable and precise information on the sexual and reproductive health needs of marginalised populations (Groce, 2004; WHO and UNFPA, 2009). Unfortunately, collecting information on the joint distribution of marginalised populations and their sexual and reproductive health poses several levels of difficulty to national statistical agencies. For instance, budgetary constraints may make the designing of new nationally representative surveys which targets marginalised population's sexual and reproductive health behaviours not feasible (Moriarity and Scheuren, 2001; Donatiello *et al.*, 2014). The reporting burden that survey participants experience due to the large amount of information collected during a single survey may also make the design of new surveys not feasible. A better solution to these difficulties is to add questions on marginalised populations to the existing efforts such as the Demographic and Health Survey (DHS), Multiple Indicator Cluster Surveys (MICS) and Indicator Household Surveys (HIS). If this is not possible, then statistical matching techniques could be a valid alternative (Donatiello *et al.*, 2014).

In Malawi, there is no dataset that jointly observed the sexual and reproductive health of persons with disabilities and their functional status. To address this limitation, the 2003 Malawi World Health Survey (MWHS-2003) and the Malawi Demographic and Health Survey (MDHS-2004) have been combined to produce a synthetic dataset for studying the link between disability measurement and sexual and reproductive health services. This chapter, therefore, focuses on the application of the statistical matching technique to the two distinct sample surveys. The datasets have been combined using a disability variable in the MWHS-2003 and parity in the MDHS-2004. It is worth noting that there exists no auxiliary information on the statistical relationship between disability and parity, therefore the statistical matching process has been performed under the *conditional independence assumption* (CIA), i.e. independence between disability and parity given some common information in both data sources and some uncertainty. To improve the quality of the matching procedure, the marginal distribution of the common variables in the two datasets has been harmonised.

6.2   Method and data for addressing data deficiencies in disability measurement:

6.2.1   Statistical matching

Statistical matching is a technique used by practitioners to combine information from distinct data sources referring to the same target population (Moriarity and Scheuren, 2001; D'Orazio, Di Zio and Scanu, 2006). The technique often involves two data files A and B, where A and B share a set of common variables *X*, with variables *Y* observed only in A and variables *Z* observed only in B. The objective of statistical matching is to estimate the correlation coefficient between *Y* and *Z* conditional on *X* variables at a macro level or to create a synthetic data source in which all the variables X,Y and *Z* are available-micro case (Moriarity and Scheuren, 2001; D'Orazio, 2016).

Statistical matching is used in situations where variables of interest are not readily available in one data source and when two or more data sources do not have unique identifiers for merging or linking the variables (Rubin, 1986; Moriarity and Scheuren, 2001; D'Orazio, 2016). For example, Simonson et al (2012) in their study of life course and old age incomes of Germany baby boomers failed to obtain a dataset that contained information on life course and old age income (Simonson, Gordo and Kelle, 2012). To obtain such a dataset, they statistically matched the German Ageing survey and the Active Pension accounts to estimate the effect of changes in life course on an individual's financial situation. In addition to the absence of unique identifiers, statistical matching can also be used in situations where detailed information for a particular topic entails development of long questionnaires which tend to have a lower response quality and a higher frequency of missing responses (D'Orazio, Di Zio and Scanu, 2006). In these situations, statistical matching is used to reduce high missing response rates and improve response quality.

The problem with statistical matching is its outcome measures, which contain some levels of uncertainty due to the inability of the statistical matching technique to create true *Y* data for File A or true *Z* data for file B (Rubin, 1986). To solve this problem, a number of researchers, including Rubin D.B (1986), Marcello et al (2006) and Zhang L (2015) have devised techniques of file concatenation with adjusted weights (Rubin, 1986), use of logical constraints (Marcello, Di Zio and Scanu, 2006), and use of proxy variables (Zhang, 2015). In file concatenation, a database with imputed values is created by treating the two databases (A and B) as probability samples from the same population. The imputed values reflect the uncertainty of the values from which they have been imputed (Rubin, 1986). Logical constraints, on the other hand, are rules that make some of

the parameter vectors in the joint distribution illogical for the investigated phenomenon. Logical constraints are introduced in statistical matching to eliminate impossible worlds (D'Orazio, Di Zio and Scanu, 2006; Marcello, Di Zio and Scanu, 2006). For example, in the matching of datasets by age and marital status, a rule can be introduced such that it is not possible for a unit in a population to be both ten years old and married.

The other critical problem of statistical matching is the assumption that the distribution of Y given X is independent of the distribution of Z given X (*Conditional Independence Assumption*) (D'Orazio, Di Zio and Scanu, 2006). The problem with this assumption is that it rarely holds in practice and that it cannot be tested from the datasets (Leulescu and Agafitei, 2013). In situations where the assumption does not hold and no additional information is available to exploit the distribution of Y and Z, it is assumed that the model used to estimate the association between Y and Z has identification problems and that the artificial dataset produced may lead to incorrect inferences. To overcome the conditional independence assumption problem, two solutions have been suggested; the first one is the use of some auxiliary information in the form of a small subset containing all the variables (X, Y, Z) or just (Y, Z) to explore the joint distribution of Y and Z (D'Orazio, 2011; Leulescu and Agafitei, 2013). The second one is the use of proxy variables with high predictive power. The proxy variables help mediate the relationship between Y and Z and make the conditional independence assumption hold true (Leulescu and Agafitei, 2013).

6.2.2 Data used to address data deficiency issues

The datasets used here to conduct statistical matching are the MWHS-2003and the MDHS-2004. The MWHS-2003 is a nationally representative dataset that contains comprehensive information on the health states of individuals based on the eight health domains of the ICF framework (World Health Organization, 2003). This dataset is used as a recipient dataset. The MDHS-2004 dataset, on the other hand, is used as a donor dataset. The MDHS-2004 is a nationally representative sample of women aged between 15 and 49, and was conducted close to the MWHS 2003. The assumption is that the demographic characteristics of the sampled population in the MDHS-2004 are similar to the characteristics of the MWHS-2003 sample. The objective and sampling design of the MWHS-2003 and the MDHS-2004 have already been discussed in sections 3.3 and 3.4 of the methodology chapter.

6.2.3 Study variables

The variables of interest in this analysis are "*disability*" and "parity" (total number of children born to a woman). Disability is a variable of interest because the desired objective is to match the

sexual and reproductive health behaviour of women with disabilities in the MWHS-2003 dataset with those of the MDHS-2004 dataset. Disability (Y) is a continuous variable created from self-reported responses about difficulties in functioning in affect, cognition, interpersonal activities, mobility, pain and discomfort, self-care, sleep and energy, and vision (Murray and Lopez, 1996; World Health Organization, 2003). To create the disability variables, Item- Response Theory (IRT) has been used to score the eight health domains, and to calculate a composite disability score, ranging from zero (absence of disability) to 100 (complete disability) (Hosseinpoor *et al.*, 2016).

The variable parity has been chosen for statistical matching because research has shown that women who give birth to a large number of children are at an increased risk of disabling conditions (Spence, 2008; Whiteford *et al.*, 2013). Parity (Z) in this study is a categorical variable with categories "low-risk parity" (having fewer than four children) and "high-risk parity" (more than four children). This variable has been transformed to risk parity because having five or more children increases the risk of poor health in women (Grundy and Holt, 2000).

The common variables denoted by X are place of residence, the age of participant, level of education, marital status and sexual activity. These variables are available in both the MWHS-2003 and the MDHS-2004 datasets. The statistical matching procedure thus involves the integration of the MWHS-2003 with the MDHS-2004, as illustrated in figure 6.2:1;

Figure 6.2:1 Graphical representation of the statistical matching technique

Recipient dataset (MWHS-2003)

(Weber and Weber, 2013)
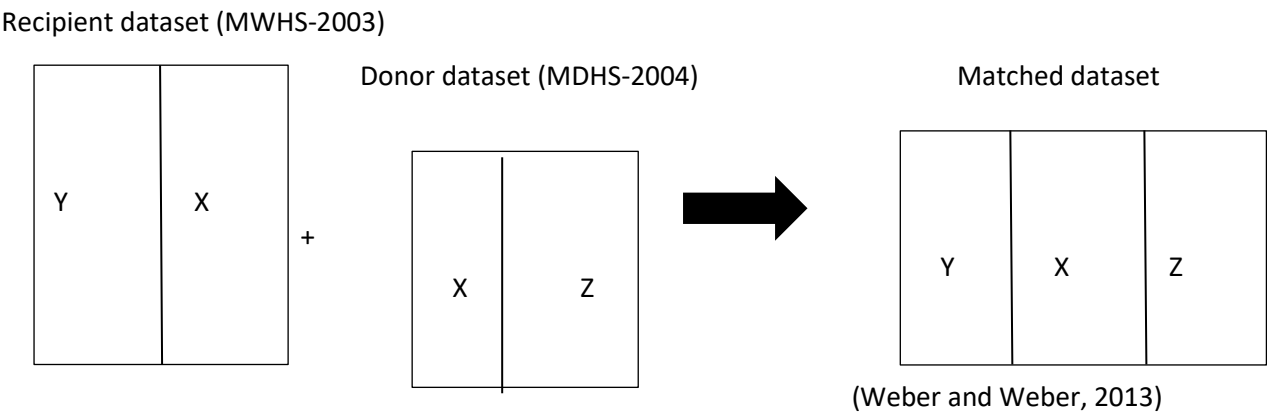
6.3   Analysis of data using statistical matching

6.3.1   Harmonisation of sources

Before starting the process of statistical matching, common variables in the MWHS-2003 and the MDHS-2004 were harmonised to facilitate the coherence of the datasets. The name of the participant-id variable in the MDHS-2004 was renamed to match that of the MWHS-2003 dataset. The categories for age, marital status and level of education of both datasets were also re-categorised to create same level categories. A new variable, sexually active, was also created in both datasets, from the question "when was the last time you had sexual intercourse?" The sexually active variable was created because of the need for a health variable that can be used in the statistical matching process. The value labels of the place of residence in the MWHS-2003 were also reclassified into a dummy variable 0=rural and 1= urban to match MDHS-2004 variable labels.

Apart from variable harmonisation, the two datasets were also adjusted for missing values. This was achieved by removing irrelevant values. For example in the MWHS-2003, all male participants and female participants aged 50 and above were removed from the dataset. This is because data for the MDHS-2004 was collected from female participants aged between 15 and 49. Participants aged below 18 in the MDHS-2004 were also removed because the MWHS-2003 data only collected information from people aged 18 and over.

In addition to adjusting for missing values and sample populations, frequency analysis of the common variables was conducted to examine proportional distributions. Examination of the proportional distributions was important because it is the proportional distribution of the matching variables that determines the marginal distribution of the imputed values.

6.3.2   Derivation of the disability variable

Creation of the disability variable was achieved through the use of a Rating Scale Model of the Item Response Theory (IRT RSM) in STATA. The Rating Scale Model of IRT was used to derive a disability variable because disability is an abstract idea that cannot be measured directly. Disability is thus measured through a set of questions or items. In the 2003 Malawi World Health Survey, 16 items, two for each domain were used to measure disability. The other reason for using the Rating Scale Model is that when measuring disability using the eight domains of functioning, all the items were rated at an ordered scale of 1 to 5. The ordering of the responses from no difficulty to extreme difficulty meant that other models of the Item Response Theory,

such as Partial Credit Model, could not be used because they do not model ordered response items (van der Linden and Hambleton, 2013).

When modelling responses using IRT, we are modelling the probability of a person responding to an item in a particular manner with respect to the person's standing on the trait that is being modelled (Ostini and Nering, 2006). In this study, it is the probability of choosing a particular category of an item with respect to the person's functioning level or functioning difficulty that is being modelled. In probabilistic terms, the question being asked is how is a person with a higher level of functioning difficulty likely to provide a response in a different response category to a person with a low functioning difficulty or no disability (Ostini and Nering, 2006; van der Linden and Hambleton, 2013). Given n polychromous test items where $i=1,…,n$, where the response U_i on test item i can take the values $h=1, …,m$.

The response function to item i, category h can be written as

$$P_{ih} = Prob\ (U_i = h) \qquad\qquad (6.1)$$

(van der Linden and Hambleton, 2013)

Since the response function is assumed to depend on the value of the person's ability or latent trait that describes the person; equation 1 above can also be rewritten as;

$$P_{ih} = P_{ih}(\theta) \qquad\qquad (6.2)$$

Where (θ) is the latent trait

In modelling the responses to the eight health domains, using IRT, it is assumed that there is a monotonic (best relationship displayed as an "S" shaped curve) between the latent trait and the probability of responding to an item of testing scale (Reeve and Fayers, 2005; Yang, 2014). In this study, it is assumed that there is a monotonic relationship between an individual's level of functional difficulty (latent trait) and the individual's response to the 16 items on the disability scale. In modelling using IRT, it is also assumed that the estimation of the item parameters and the latent trait are independent of the participant's characteristics such as age (Yang, 2014). This means that the item parameters that are estimated by the IRT RSM model for the mobility question such as "how much difficulty did you have with moving around?" does not differ according to a person's age (either 20-24 or 50-54). In IRT RSM modelling, there is also an assumption of local independence (Ostini and Nering, 2006; Yang, 2014). In this instance, it is assumed that a person's response to a particular item (e.g. mobility item) is independent of the

response to the other item (e.g. self-care item). This means that the response given to a mobility question does not depend on the response given to a self-care item.

Mathematically the Rating Scale Model of IRT is described as

$$P_{ih} = \frac{e^{\sum_{h=0}^{m}[\theta - (b_i + \tau_h)]}}{\sum_{g=0}^{l} e^{\sum_{h=0}^{g}[\theta - (b_i + \tau_h)]}}$$ (6.3)

(Ostini and Nering, 2006)

Where:

θ= is the participants' latent trait (or functioning difficulty in this study)

τ_h= (slope) parameter or the item discriminant

b_i = is the location parameter or item difficulty

The item discriminant τ_h which is also known as the slope parameter "allows for determining how well items identify participants at different levels of the latent trait", (Yang, 2014). When an item has a steeper slope it indicates that it is a good discriminant, and when the slope is less steep it indicates that the item is a poor discriminant. Theoretically, the item discriminant τ_h is supposed to range from$-\infty\ to\ +\infty$, but when an item has a negative item discriminant it is perceived as being problematic (Ostini and Nering, 2006; Yang, 2014). The item is considered problematic because it indicates that survey participants with an increased level of the latent trait are less likely to choose the more severe response options (Yang, 2014). In other words, if a mobility item, which is supposed to help identify people with higher levels of mobility difficulty has a negative item discriminant; it indicates that participants with higher levels of mobility difficulty are less likely to choose higher order categories such as severe or extreme.

The item difficulty b_i on other hand is used to describe "how difficult it is to achieve a 0.5 probability of a correct response for a specific item given the participant's level of the latent variable (θ) (Yang, 2014). A higher value of an item difficulty parameter b_i indicates that it is difficult for participants to correctly answer an item and that a higher ability level is needed to attain that goal (Reeve and Fayers, 2005; Yang, 2014). For a polychromous item, the item difficulty parameter describes the difficulty of achieving a 0.5 probability of correctly answering a particular category instead of its preceding category. In this study, the item difficulty parameter helps to describe, for example, the 0.5 probability of answering mild difficulty instead of no difficulty.

6.3.3   Selection of matching variables

In statistical matching applications, datasets A and B may share many common variables, but it is only the most *relevant variable*s (variables that significantly explain the variation in the target variables, in this case, disability and parity) that are used in the matching process (D'Orazio, 2011; Weber and Weber, 2013). The selection of these variables is performed using descriptive or inferential methodologies. In this study, the selection of matching variables involved the use of Spearman rho correlation, Chi-square and uncertainty measures of association.

Spearman rho

Spearman rho correlation is a measure that is used to test the strength of the relationship between two variables. Spearman rho correlation was conducted instead of Pearson correlation because it determines the strength and direction of the monotonic relationship between two variables rather than the strength and direction of the linear relationship between two variables (Harrell, 2015). A linear relationship between two variables is not relevant in statistical matching because of proportional distributional changes that may occur to a particular variable, due to the statistical technique. To account for an eventual nonlinear relationship, it is necessary to consider ranks for each variable instead of raw data (D'Orazio, 2016). Spearman's rho can have any value between -1 and +1 (Zar, 1998). A value of 0 indicates no relationship and values of ±1 indicate a one-to-one relationship between variables or 'perfect correlation'. The Spearman's rho correlation coefficient can also be squared to produce a coefficient of determination(R^2), which measures the amount of variability in one variable that is shared by the other variable (Field, 2013).

Chi-square test

The Chi-square test is another measure of association that is used to determine the association between two categorical variables. Parity is a categorical variable, which is why it was appropriate to use the Chi-square test of association to measure the relationship between parity and the common variables. The Chi-square test produces a number of test statistics, but this paper concentrates on the post-estimation outputs because the focus is on assessing the power of common variables in predicting the variation in parity. Therefore, only Cramer's V, Goodman-Kruskal lambda (λ) and Goodman-Kruskal tau (τ) were used as measures of association.

Cramer's V is a Chi-square measure of association that is used to determine the strength of association between two categorical variables (Agresti A, 2007). Its values range from 0 (no relationship) to 1 (a strong relationship between the two variables).

Goodman – Kruskal lambda (λ) is another measure of Chi-square based association. It measures the proportional reduction in error that is achieved when membership of a category of one variable is used to predict category membership of the other variable (Field, 2013). Its values range from 0 (one variable does not predict the other) to 1(one variable perfectly predicts the other).

In addition to Goodman-Kruskal lambda (λ), Goodman-Kruskal tau (T) was also used to select common variables. Goodman-Kruskal tau (T) is the same as Goodman-Kruskal lambda (λ), except that it measures the proportional reduction in error that is achieved by assigning probabilities specified by marginal or conditional proportions (Reynolds, 1984). Goodman-Kruskal tau (T) *has* values 0 (no association) and 1 (complete or perfect association).

Uncertainty test

In addition to pairwise association, a test for uncertainty reduction was also conducted to assist in the selection of matching variables. This is done by selecting just those common variables with the highest contribution to the reduction of *uncertainty* i.e. the impact of the absence of joint information on disability (*Y*) and parity (*Z*) on the estimates of the joint (*Y, Z*) parameters (D'Orazio, Di Zio and Scanu, 2010; D'Orazio, 2011; Weber and Weber, 2013). The reduction of uncertainty used in this analysis is that explained by D'Orazio M in the "Statistical Matching and Imputation of Survey Data with Stat Match", paper (D'Orazio, 2016). The reduction of uncertainty technique allows exploration of uncertainty when all the variables (X, Y, and Z) are categorical. It estimates the likely interval values for the probabilities in the contingency table Y x Z as given by the Fréchet bound:

$$max\{0, P(Y) + P(Z) - 1\} \leq P(Y \cap Z) \leq min\{P(Y), P(Z)\} \qquad (6.4)$$

Where P(Y) is the probability of event Y happening and P (Z) is the probability of event Z happening independently.

Assuming that X_D relates to the complete crossing of the matching variables X_M, it can be shown that

$$P_{j,k}^{(low)} \leq P_{Y=j,Z=k} \leq P_{j,k}^{(up)} \qquad (6.5)$$

Where;

$$P_{j,k}^{(low)} = \sum_i P_{X_D=i} \times max\{0; P_{Y=j|X_D=i} + P_{Z=k|X_D=i} - 1\}$$

$$P_{j,k}^{(up)} = \sum_i P_{X_D=i} \times min\{P_{Y=j|X_D=i}; P_{Z=k|X_D=i}\}$$

For j=1,…., J and k=1,….,K where J and K are categories of Y and Z respectively (D'Orazio, 2011).

And:

P_{X_D}:   Probability of the complete crossing of the matching variables

$P_{Y=j|X_D=i}$ Probability of disability given a complete crossing of matching variables

$P_{Z=k|X_D=i}$ Probability of parity given a complete crossing of matching variables

Therefore, for each cell in the contingency table Y x Z for all possible combinations of the input *X* variables, the reduction of uncertainty is measured by the average widths of the interval:

$$\bar{d} = \frac{1}{J \times K} \Sigma_{j,k} \left(\hat{p}_{j,k}^{(up)} - \hat{p}_{j,}^{(low)} \right) \tag{6.6}$$

The reduction of uncertainty output reports the possible combination of *X* variables that can be used for matching. It also reports the number of cells in each of the input tables and the corresponding number of cells with a frequency equal to 0. The analysis also provides the average width of the uncertainty intervals [0, 1] and its relative value [0, 1] when compared with the average widths of the uncertainty intervals when no *X* variables are considered (D'Orazio, 2011; D'Orazio, Di Zio and Scanu, 2012; D'Orazio, 2016).

Note: Common variables that were not strongly associated with disability or parity were regarded as redundant predictors and were removed from the matching set.

6.3.4   Weight calibration

When matching complex sample surveys, it is important to take into account the sampling design and the corresponding sampling weights of the sample surveys to achieve consistency between estimates (mainly totals) computed separately from the two data sources (D'Orazio, 2011). In this study, the sampling design and the corresponding sampling weight of the MWHS-2003 and MDHS-2004 were incorporated into the statistical matching process through weight calibration of the common variables. Calibration of weights is a common technique in sample surveys; and is

used for adjusting probability sampling weights to increase the precision of estimates, account for unit nonresponse or frame errors, or force internal estimates to be consistent with external measures (Kott, 2012). In adjusting the probabilities of sampling weights, the technique fulfils a series of constraints concerning totals for a set of auxiliary variables (D'Orazio, 2011).

There are a number of procedures for calibrating survey weights in population studies, these include; the general regression estimator "GREG" (Deville and Särndal, 1992); optimal calibration estimator (Wu, 2003); local polynomial regression estimator (Breidt and Opsomer, 2000) and Renssen calibration technique (Renssen, 1998). The general regression estimator, optimal calibration estimator and local polynomial estimator are a family of regression estimators, which are used to weight auxiliary information in surveys with high nonresponse rates. The three regression estimators only differ from each other when measuring the distance between *Y* and the X variables (Deville and Särndal, 1992; Wu, 2003; Park and Fuller, 2012). The Renssen calibration estimator, on the other hand, calibrates the marginal distribution of two categorical variables and is a mix between calibration and statistical matching (Renssen, 1998). The Renssen estimator is also useful for imputing values of one large sample (donor dataset) into another large sample (host dataset). Furthermore, it is a technique that can be modified to estimate the marginal distribution of continuous variables.

Assuming there are two complex survey datasets A and B, sharing a set of matching variables X_M with variable Y only observed in dataset A and variable Z only observed in dataset B; and variables (X_D, Y, Z) are all categorical variables, with X_D being a complete or an incomplete crossing of the matching variables X_M (D'Orazio, 2011). The first step of the Remsen calibration procedure consists of calibrating weights in A and B using X_M as control variables such that when the new weights are applied to the set of X_D variables they should reproduce some known (or estimated) population totals (Renssen, 1998; D'Orazio, 2011). In situations where the population totals of X_M are known, the totals are passed to the statistical software for reproduction, but when the population totals are unknown they are estimated by a weighted average of the totals estimated on the two surveys by;

$$\tilde{t}_{X_D} = \lambda \hat{t}_{X_D}^{(A)} + (1 - \lambda)\hat{t}_{X_D}^{(B)} \qquad\qquad (6.7)$$

Where λ= n_A / (n_A +n_B) , and (n_A and n_B are the sample sizes of A and B respectively) (D'Orazio, 2011 , p23).

$\hat{t}_{X_D}^{(A)}$ = total of the crossed matching variables in dataset A

$\hat{t}_{X_D}^{(B)}$ = total of the crossed matching variables in dataset B

The weighting of matching variables using the Renseen calibration procedure reduces the variances of the estimated marginal counts but maintains the variances of the estimated cell counts (Renssen, 1998). This, in turn, reduces the standard errors of the synthetic variables.

To ensure consistency of the estimated totals of the imputed values, the marginal distributions of the common variables were weighted using the Renseen procedure. The validity of the weighting process was achieved through comparison of the marginal distributions of the matching variables using similarity and dissimilarity measures. The similarity and dissimilarity measures include;

The dissimilarity index or Total Variation Distance ("tvd"); this is the smallest fraction of units that need to be reclassified in order to make the distribution equal. It ranges from 0 (minimum dissimilarity) to 1. The rule of thumb for this dissimilarity index is D<0.03;   Thus a dissimilarity index with value less than 0.03 indicates that the estimated distribution follows the true or expected pattern quite closely.

The other similarity or dissimilarity measure is "*Overlap*"; this is a measure of similarity which ranges from 0 to 1 (the distributions are equal).

Bhattacharyya coefficient is another measure of similarity which ranges from 0 to 1 (the distributions are equal).

Hellinger's Distance: Is another dissimilarity measure which ranges from 0 (distributions are equal) to 1 (maximum dissimilarity).

6.3.5   Statistical matching of the MWHS-2003 and MDHS-2004

The statistical matching technique used in this study is the constrained nearest neighbour hot-deck. This is a non-parametric micro matching method often used under the assumption of conditional independence. The technique allows each record in the donor file to be used only once, as long as the donor file is larger or equal to the recipient file (Leulescu and Agafitei, 2013). Donors are selected based on the minimal distance between donor and recipient record conditioned by the preservation of weights in both datasets. This process ensures the preservation of the marginal distribution of the imputed variables in the synthetic dataset (D'Orazio, Di Zio and Scanu, 2006; Leulescu and Agafitei, 2013). The main problem with this technique is that when there are more donors than recipients, it is difficult to minimise the overall matching distance and this leads to a linear programming problem whose solution requires sizeable computational efforts (D'Orazio, Di Zio and Scanu, 2006).

In this study, the MWHS-2003 data set denoted as *A* is the recipient file and the MDHS-2004 denoted *B* is the donor file. In statistically matching dataset A and B; each record in recipient file A is matched with the closest record in the donor file B according to a Manhattan (city-block) distance measure computed using the matching variables X_M. This means that the donor for the αth record in the recipient file *A* is chosen so that;

$$d_{ab^*} = \left|x_a^A - x_{b^*}^B\right| = \min_{1 \leq b \leq n_B}\left|x_a^A - x_b^B\right| \tag{6.7}$$

When two or more donor records are equally distanced from a recipient record, only one donor is chosen by solving a travelling salesperson problem (*Hungarian* method) (D'Orazio, 2011).

The Manhattan distance measure used in selecting matching records is a distance function that calculates the absolute distance between the categories of the recipient record and the categories of a potential donor record summed across the selected matching variables (de Waal, 2015). The Manhattan distance function assumes that each category of the variable has been numbered. The absolute difference between the two numbers for the two records involved then translates into the absolute distance for a variable. The assumption of this distance between each record is computed by the following function;

$$d_{ab} = \sum_{P=1}^{P} c_p \left|x_{ap} - x_{bp}\right| \tag{6.8}$$

Where α=1,….,n; b=1,….., n; P-is the dimension of the record; $d_{ab} \geq 0$ and c_p is a scaling factor for the p_{th} variable (D'Orazio, Di Zio and Scanu, 2006).

Manhattan distance measure has been used for selecting matching records instead of propensity scores in this study because propensity score matching increases data imbalance; which in-turn increases the bound on the degree of model dependence in the statistical estimation of causal inference (King and Nielsen, 2016). According to King et al (2016) propensity score matching causes damage to the data by continuing to prune observations after it has nearly accomplished its goal of approximating a completely randomised experiment. In the evaluation of real-life programs like the impact of employment promotional programs, propensity score matching has been found to generate incorrect estimates even under ideal circumstances compared to randomised experiments (Peikes, Moreno and Orzol, 2012)

6.3.6   Assessment of the accuracy of the statistical matching results

Following the statistical matching procedure, it was necessary to evaluate the accuracy of the matching results, even though research has proven that it is difficult to do so (D'Orazio, Di Zio and Scanu, 2012; Leulescu and Agafitei, 2013). Accuracy assessment of statistical matching results

is difficult because in statistical matching the relationship of phenomena not jointly observed is studied (DOrazio, 2013).   The statistical matching process may also provide different outputs, like a synthetic data set in the micro case or estimates of parameters (e.g. correlation coefficient) in the macro case. The available data sources may also have different quality levels (sampling design, sample size and data processing steps).

The aim of conducting statistical matching in this study was to produce a synthetic dataset that will be used for statistical inference. Therefore, it was necessary to evaluate the accuracy of the synthetic dataset. This was achieved by first examining how the synthetic dataset preserved the marginal distribution of the imputed variable parity, (by comparing it with the marginal distribution of parity variable estimated from the donor dataset =MDHS dataset). The second step was to examine how the synthetic data set preserved the joint distribution of the imputed variable with the matching variables (the reference was the joint distribution of the estimates from the donor data set=MDHS dataset) (DOrazio, 2013). The comparison of the marginal distribution of parity between the synthetic dataset and the donor dataset was accomplished by means of similarity or dissimilarity measures (total variation distance, Overlap, Hellinger's Distance and Bhattacharyya coefficient).

A descriptive analysis of the imputed variables including risk parity, body mass index, and assistance during delivery was also conducted to compare the proportional distribution of the imputed variables from the donor dataset (MDHS-2004).

6.4   Results of the technique of statistical matching

6.4.1   Harmonisation of Data sources

The proportional distribution of the matching variables; place of residence, the age of participant, level of education, marital status and sexual activity in the two datasets are presented in table 6.4:1 (MWHS-2003and MDHS-2004). The results indicate that the proportional distributions of the matching variables in the two datasets are almost the same. For example, place of residence in both samples has a high proportion of people in rural areas compared to urban areas. For the MDHS-2004 data, 82.34% of participants live in rural areas compared to 17.66% in urban areas. The same applies to the MWHS-2003 data whose proportional distribution is 83.62% rural and 16.38% urban.

The table also demonstrates that both surveys sampled a higher proportion of young people aged 18-24 (MDHS-2004: 37.87% and MWHS-2003: 38.44% respectively) compared to older people aged 35-49 (MDHS-2004: 27.04% and MWHS-2003: 26.49% respectively. Both surveys also sampled a higher proportion of people with primary education (MDHS-2004: 59.75% and MWHS-2003: 70.35%) compared to those with no education, secondary or higher. In terms of marital status, both samples had a higher proportion of married or cohabiting women (MDHS-2004: 78.23% and 74.19% for the MWHS-2003) compared to other marital categories (never married, separated or divorced and widowed). The table further illustrates that more than 50% of the sampled population in both datasets were sexually active (59.87% for MDHS-2004 and 60.47% for the MWHS-2003 survey).

Table 6.4:1 Proportional distribution of common variables

Variable	MDHS-2004		MWHS-2003	
	%	n	%	n
Place of residence				
Urban	17.7	1,828	16.4	387
Rural	82.3	8,525	83.6	1978
Total	100	10,353	100	2365
Age Group				
18-24	37.9	3,921	38.4	909
25-34	35.1	3,633	35.1	829
35-49	27.0	2,799	26.5	626
Total	100	10,353	100	2365
Marital status				
Never Married	8.3	862	9.8	231
Married or cohabiting	78.2	8,099	74.2	1755
Separated or divorced	9.2	956	12.0	283
Widowed	4.2	436	4.1	97
Total	100	10,353	100	2365
Level of education				
No education	25.0	2,589	24.6	582
Primary	59.8	6,186	70.4	1663
secondary+	15.2	1,578	5.0	120
Total	100	10,353	100	2365
Sexual activity				
Not active	40.1	4,155	39.5	935
Active	59.9	6,198	60.5	1430
Total	100	10,353	100	2,365

6.4.2 Derivation of the disability index using Rating Scale Model of the Item Response Theory (IRT RSM)

The rating scale model of the Item response theory was used to create a disability index on functioning difficulty. The aim of creating a disability index using the rating scale model was to

obtain functioning scores that were not affected by personal characteristics such as age or the ordering of the categories of the rating scale. During the derivation of the individual score for each health domain (mobility, self-care, pain and discomfort, cognition, interpersonal activities, vision, sleep and energy and affect), a number of outputs were generated. These outputs help explain the experience of the participants when rating their functioning difficulties. The results also help to assess the reliability of the eight domains in measuring disability. The following paragraphs discuss the results of the rating scale model.

6.4.2.1 Category Characteristic Curve (CCC)

In modelling the disability index, the first step was to examine the survey participant's probability of selecting one of the response categories. Figure 6.4:1 presents the Category Characteristic Curve (CCC) for the item: "overall in the last 30 days, how much difficulty did you have with moving around?" This question is one of the questions of the mobility domain. The latent variable disability or functioning difficulty is represented by theta along the horizontal x-axis (Reeve and Fayers, 2005). People with no difficulty in functioning are to the left of the axis while people with extreme functioning difficulty are to the right. Numbers on the x-axis are the different levels of functioning. Thus a difficulty score of theta (θ =-4.0) indicates that the person has a lower level of difficulty or no difficulty in functioning. The vertical axis indicates the probability that a person will select one of the item response categories with respect to their level of functioning.

Figure 6.4:1, illustrates that participants with lower levels of functioning difficulties (e.g. θ= -2.0) had a high probability of answering 'none or no difficulty' compared to the other categories. Moving to the right along the theta (θ)-axis, participants with functioning difficulty of above 2 had a low probability of choosing the moderate category but were more likely to select severe or extreme categories. The points where the adjacent categories cross indicate transitions from one category to the next. For example, the no difficulty and mild difficulty categories crossed each other at the theta level of θ=1. This means that participants with a functioning theta of approximately θ= 1.0 were more likely to select mild difficulty compared to no difficulty. The figure further indicates that participants with functioning difficulties of approximately θ=2.5 experienced difficulties in selecting mild, moderate or severe responses of this mobility item.

Figure 6.4:1Category Characteristics Curve (CCCs) of the mobility domain
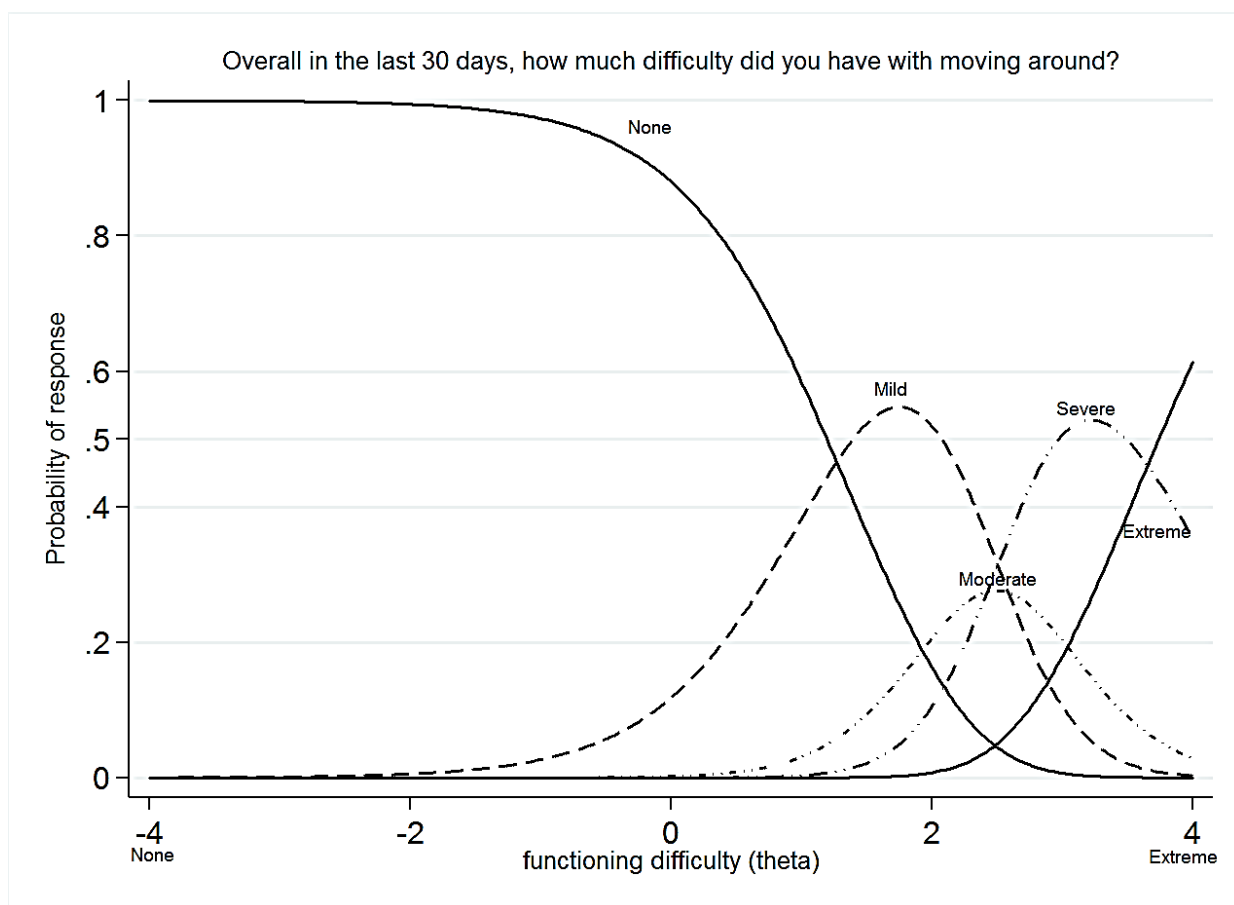
The CCC models the probability of each response (None, mild, moderate, Severe, Extreme) versus the theta values that measure the location of the latent trait of functioning difficulty or disability.

6.4.2.2   Item Information Functions

The second step in modelling the disability index was to assess the reliability of the domain items in measuring disability. This was achieved through the use of Item Information functions. Item Information functions provide the theta (θ) range for which the item or scale best discriminates between the participants. The Item Information function discriminates survey participants using item discrimination (τ_h) and location or threshold (b_i) parameters (Reeve and Fayers, 2005; Ostini and Nering, 2006). The Location parameters examine how a particular item matches the levels of the latent trait variable that is being measured. For a measurement scale which accurately measures the latent trait, the items should be well spaced across the continuum (Reeve and Fayers, 2005). In figure 6.4:2, the size or value of the information that the item is measuring is shown on the Y-axis. Items with a high discriminant have information functions with a high maximum value. A high discriminant indicates that the item can better differentiate participants who lie near the threshold values.

Figure 6.4:2 presents Item Information Functions for the Mobility and Pain and discomfort domains. The information function for the pain and discomfort item has a maximum value when theta (θ) is approximately 1.8. This means that the item performed well in the discrimination of people who had low to moderate levels of functioning difficulty. The Mobility domain, on the other hand, has a maximum value when theta (θ) is approximately 2.5. The distribution of the mobility item indicates that the item had a high performance in discriminating against people who had moderate to extreme levels of functioning difficulty. The high discrimination peaks of the two items as shown in figure 6.4:2 demonstrate that the two items performed well in discriminating individuals with different levels of functioning and that they contributed well to the test scale of disability.

Figure 6.4:2 IRT SRM Item Information Function of two items of the health domains
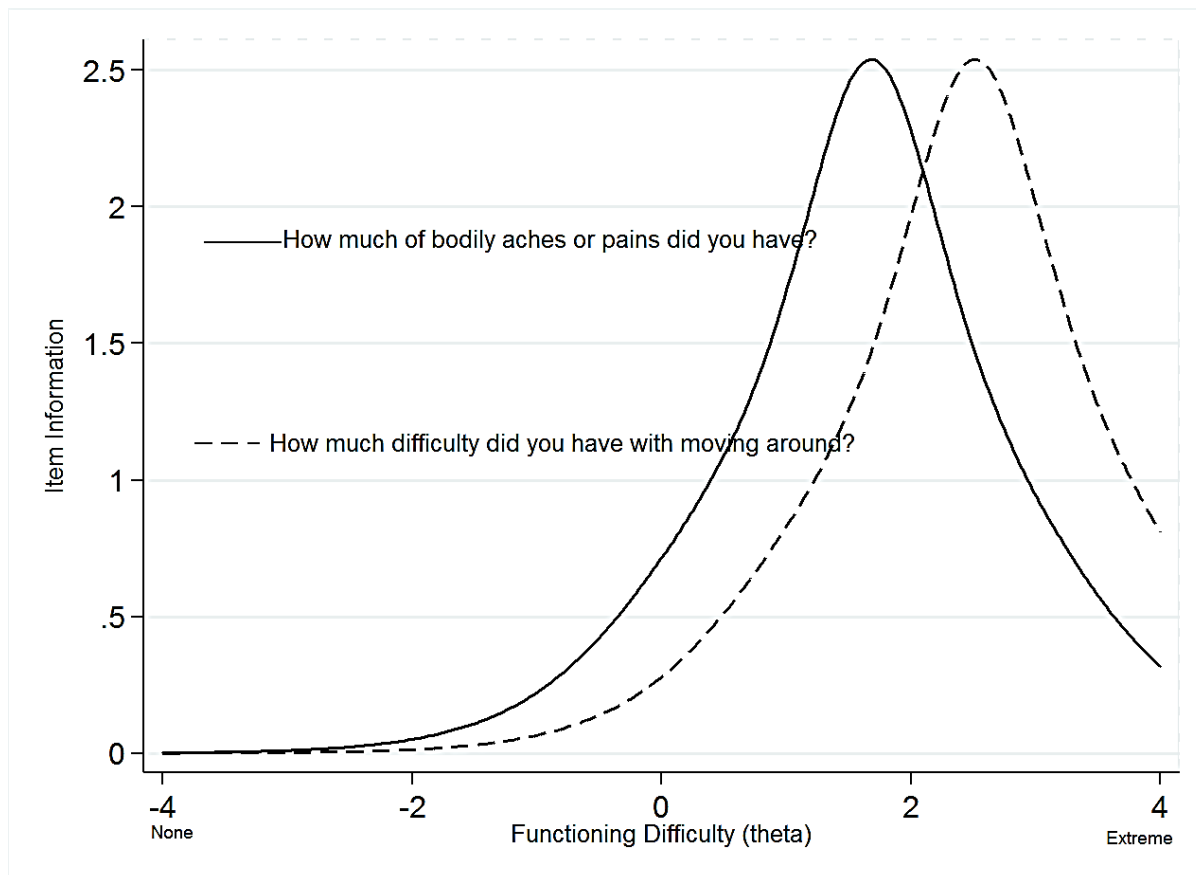
Each curve describes the range over θ for which the item precisely measures individual functioning (disability).

In addition to assessing the individual item information function, all the 16 items described in the study variable section above were also examined to understand how the overall scale was discriminating between people with different levels of functioning. Figure 6.4:3 presents the test

information scale across all 16 items. It can be deduced from the figure that all the scale items concentrated on measuring participant's difficulties in carrying out daily activities. The scale information has a maximum value at theta $\theta=2.5$, indicating that it performed well in the discrimination of people with difficulties in functioning. The R-value of $r=0.96$ also demonstrated that the 16 items were a reliable measure of functioning difficulty or disability. The dashed line in the graph represents the standard errors. An examination of the standard errors indicates the standard errors are below 0.2 on the right-hand side of the continuum and higher on the left-hand side of the continuum. This demonstrates that the functioning scale reliably measured persons with functioning difficulties or disability.

Figure 6.4:3 IRT RSM Scale information for the disability of functional limitation scale
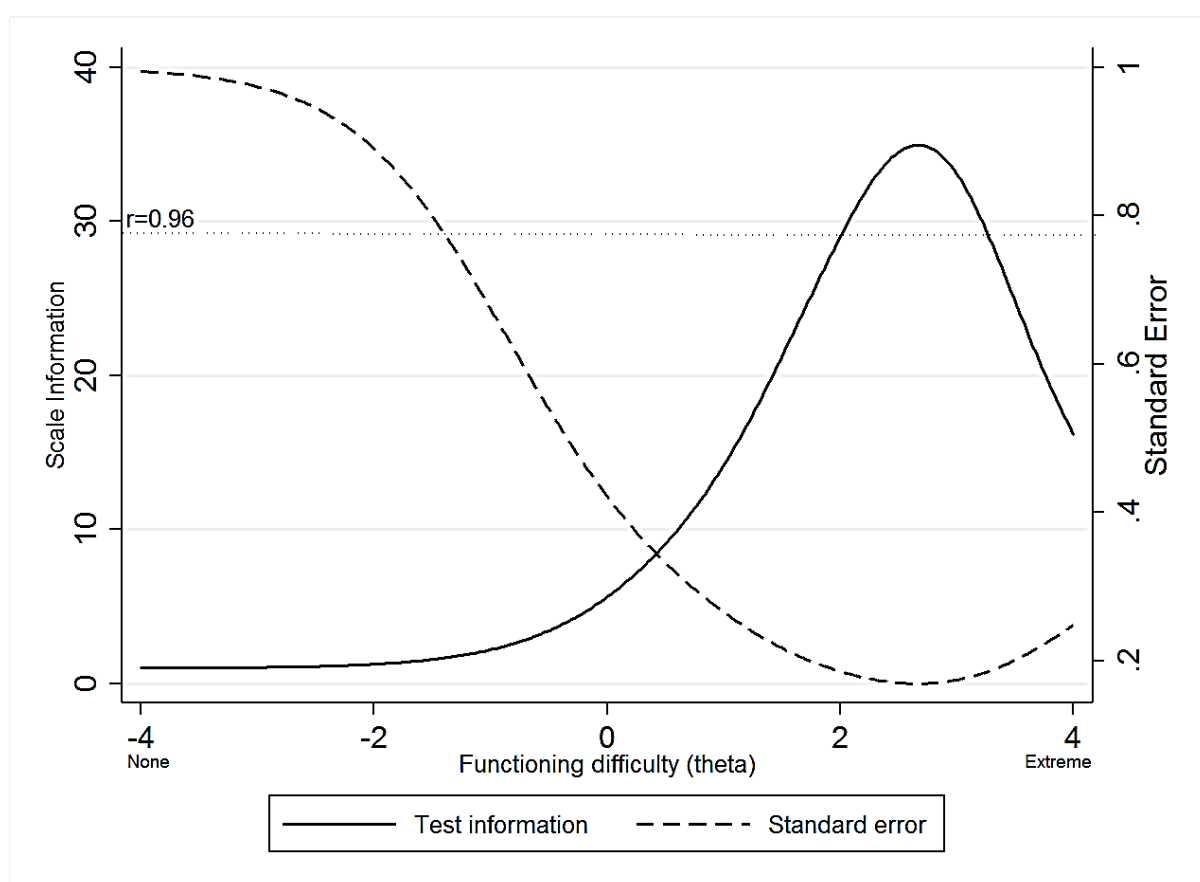
The curve indicates the range over θ for which the scale is most informative for measuring functioning difficulty levels of the survey participants. The dashed line indicates the standard error of the measurement scale. The dotted line indicates the approximate level of reliability associated with different information magnitudes.

6.4.2.3   Test Characteristic Curve (TCC)

Having examined individual responses to each category of the items and how each item was measuring the level of functioning difficulty, a test characteristic curve was also produced to evaluate the probability of correct response at each ability level for all the items in the

measurement scale (Baker and Kim, 2017). The expected score was then plotted against the observed score to assess the variability of the responses to the measurement scale. Figure 6.4:4 presents the test characteristic curve of all the 16 items of the health domains. The figure also presents a comparative analysis of the observed and expected scores.   The x-axis of the graph indicates the level of functioning difficulty (or latent trait) that a participant was expected to have to achieve the true or expected score. The y-axis presents the total score of all the 16 items of the functioning difficulty measurement scale.

  Figure 6.4:4 demonstrates that as the level of functioning difficulty increases, the expected scores also increase thus presenting a monotonically increasing function. For example, for a participant with a functioning difficulty of $\theta=2.0$ she or he was expected to have an overall score of 20. For a participant with a disability trait of 2.97, they were expected to have an overall score of 40. Figure 6.4:4, further illustrates that the theta (θ) levels for the expected scores were higher than the observed scores. For example, among those participants who had an overall functioning difficulty score of 20, their observed theta level was approximately ($\theta=1.0$) whilst their expected latent trait was ($\theta=2.0$).

Figure 6.4:4 IRT RSM Test Characteristics Curve for all of the 16 items of the health domains
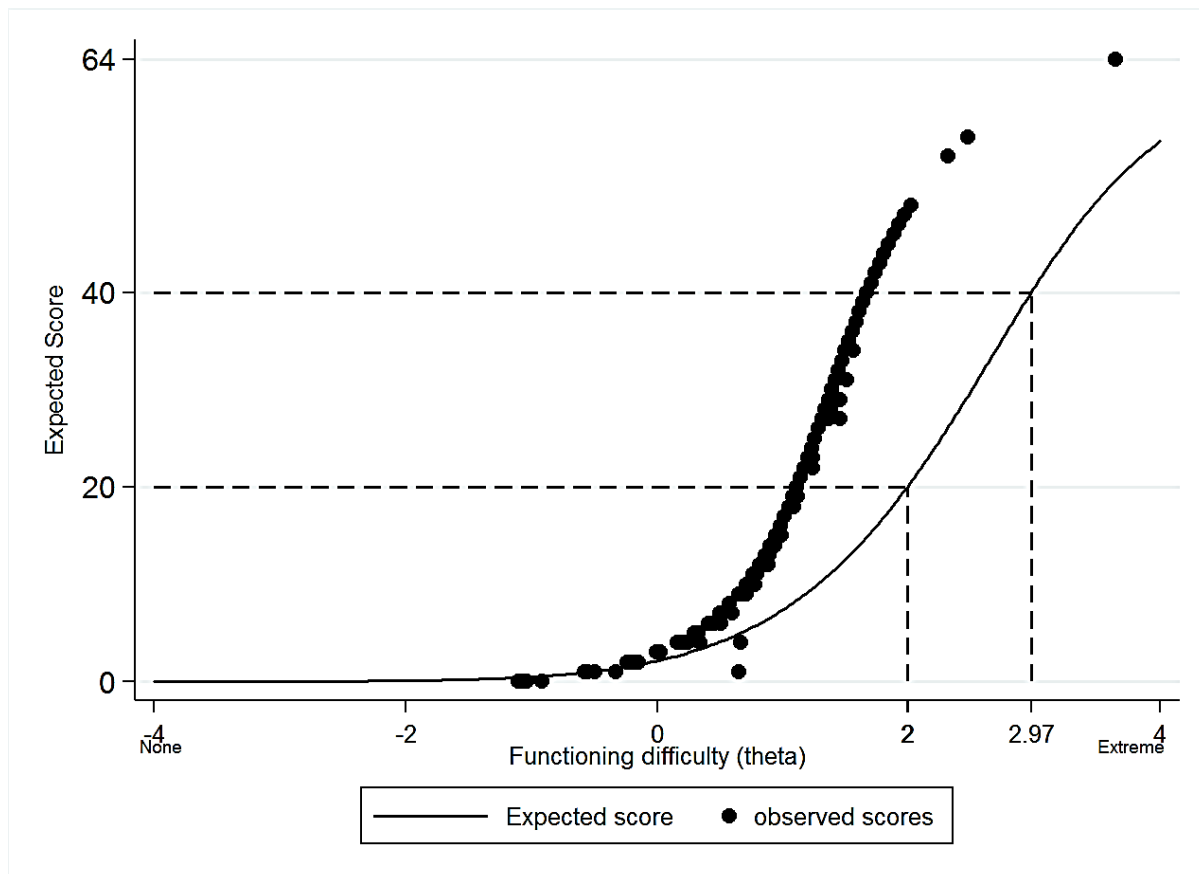
The TCC is perceived as the regression of the summed score responses on the latent trait. The dots on the scale present the observed scores conditional on the latent variable.

6.4.2.4   Selection of matching variables

Spearman rho

The process of statistical matching requires that the two datasets A and B should share some common variables. However, not all variables can be used, only the most relevant ones or (those that highly predict the variation in the variables of interest are used). In this paper, the selection of such variables was performed through the use of the Spearman rank correlation coefficient and Chi-square test.

Table 6.4:2 presents the outcome of the Spearman's rank correlation coefficient test. The results indicate that only age of a participant had a significant relationship with disability. Place of residence, level of education, sexual activity and marital status had no relationship with disability, as shown by their Spearman rho, F-statistic, p-values and adjusted rho-squared. Even though age was related to disability, the relation was a positively weak monotonic relationship as shown by the Spearman's rho value (rho2=0.003). The monotonic relationship is statistically significant with an F-value of 3.51 and an associated p-value of $p<0.05$ (p=0.030).

Table 6.4:2 Spearman rho correlation: response variable=disability or functional limitation

Variable	*rho2*	*F*	*df1*	*df2*	*P*	*Adjusted rho2*	*n*
Place of residence	0.001	2.44	1	2362	0.118	0.001	2364
Age	0.003	3.51	2	2361	0.030	0.002	2364
Education	0.001	1.44	2	2182	0.237	0.000	2185
Sexually active	0.000	0.45	1	2362	0.502	0.000	2364
Marital status	0.003	2.16	3	2360	0.090	0.001	2364

Chi-square test

Table 6.4:3 presents the Chi-square test of association results between *parity* and the matching variables. Cramer's V, Goodman-Kruskal lambda (λ) and Goodman-Kruskal tau (T) values indicate that only age predicts the variation in parity. The Cramer's V value for age is 0.634. This illustrates that age is strongly associated with Parity. The Level of education of a woman is also associated

with the total number of children born but the relationship is weak with a Cramer's V value of (0.297) There is also a weak relationship between the total number of children born and a woman's marital status as shown by the value of Cramer's V (Cramer's V=0.203). In terms of proportional reduction error, both Goodman-Kruskal lambda (λ) and tau (T) indicate that the probability of making an error in predicting the marginal proportions of *parity* reduces by 43% for each category of age (18-24, 25-34, 35-49) and by 40% for the whole variable. Place of residence, level of education, sexual activity and marital status have lower predictive power for the marginal proportions of parity.

Table 6.4:3 Chi-square test=response variable=parity

Variable	Cramer' V	Goodman-Kruskal Lambda	Goodman-Kruskal tau
Place of residence	0.101	0.000	0.010
Age	0.634	0.431	0.402
Education	0.297	0.000	0.088
Sexually active	0.025	0.000	0.001
Marital status	0.203	0.000	0.041

Uncertainty test

As well as conducting pairwise associations, an uncertainty test was also conducted to determine the combination of common variables with the highest contribution to the reduction of uncertainty. Looking at the average width of the cell bounds in table 6.4:4 below, it appears that all the common variables (X) being considered should be used as matching variables. Unfortunately, columns with zero frequencies indicate that a combination of all common variables produces a high proportion of cells with zeros. For cells with *XY* combination, 134 out of 288 consists of zeros, for *XZ* combination, 104 out of 288 have zeros. The second best choice of the common variables, even though they (produce a slight worsening of the average width of intervals (0.137 to 0.522), is a combination of the place of residence, age, marital status and level of education. However, basing on the number of common variables with the lowest zero

frequencies, place of residence, age and education are the best common combination. In this study, only age and place of residence were used as matching variables in the statistical matching process. The education variable was not used in the statistical matching process because of differences in the educational levels of the women in the MWHS-2003 and the MDHS-2004.

Table 6.4:4 Table presenting the levels of uncertainty obtained from combining the common variables

Variable Combination	*Cells with zero XY frequencies*	*Cells with zero XZ. Frequencies*	*Average width*	*Relative Average width*
Place of residence*age*Marital status *Sexually active *Education	134	104	0.136	0.517
Place of residence *Age*Marital status *Education	42	35	0.137	0.522
Place of residence*Age*Marital status *Sexually active	19	22	0.140	0.533
Place of residence *Age*Marital status	3	7	0.141	0.537
Place of residence*Age*Sexually active *Education	4	6	0.143	0.546
Place of residence*Age*education	0	3	0.144	0.549

6.4.3   Weight calibration

To ensure consistency in the estimated totals of the imputed values computed from the two data sources it was necessary that the matching variables (age and place of residence) marginal distribution be calibrated according to the sampling design and the corresponding sampling weights of the sample surveys. This process was achieved through the use of a harmonisation function in R package. After harmonisation, a dissimilarity/Similarity test was conducted to check for changes in the distribution pattern of the matching variables in the two datasets.

The results indicate that the marginal distribution pattern of the matching variables (age and place of residence) in the MWHS-2003 and the MDHS-2004 before calibration were not completely the same. About 4% (*tvd=0.038*) of the units in both datasets needed to be reclassified

to improve the distribution. The Hellinger dissimilarity index (*Hell=0.035*) also indicated that marginal distributions of the matching variables in the two samples were not similar.

After calibrating the weights through the incorporation of survey design and sampling weights, the dissimilarity index outputs showed a complete transformation of the marginal distributions. All the dissimilarity/similarity indexes (*tvd*=1.39E-16, *Overlap*=1.00e+00, *Bhatt*=1.00e+00, *Hell*=0.00e+00) indicated that the marginal distributions of the matching samples were similar. This improvement in the distribution pattern of the matching variables enabled the statistical matching process of the two datasets using constrained nearest neighbour hot-deck to be conducted.

6.4.4   Assessment of the accuracy of statistical matching

Upon completion of statistical matching, it was necessary to make an assessment of the accuracy of the created synthetic dataset. Examination of the accuracy of the dataset was conducted by comparing the marginal distribution of the computed parity variable with the parity variable in the donor dataset through use of similarity or dissimilarity measures.   The joint distribution of parity with the matching variables (age and place of residence) in the synthetic dataset was also compared with the donor dataset (MDHS-2004 datasets).

The similarity/dissimilarity measurement results indicated that the marginal distribution of parity in the synthetic dataset was similar to that of the donor dataset with an *Overlap index* value of close to 1 (*Overlap* =0.963) and an associated Bhattacharyya *coefficient* of close to 11 (*Bhatt*=0.999). A comparison of the joint distribution of parity with the matching variables in the synthetic dataset with that of the donor datasets also indicated that the joint marginal distributions of the variables in the two datasets were the same with an *Overlap index* of *0.944* and an associated *Bhattacharyya coefficient* of *0.997*.

A descriptive analysis of the reproductive variables in table 6.4:5 indicates that the proportional distribution of the imputed variables in the synthetic dataset is not different from the MDHS-2004 dataset. For example, in the MDHS-2004, the proportional distribution of women with 0 to 4 children is 69.44%, the imputed variable has a slight increase of 4% (73.1%), but the difference is not statistically significant. This proportional similarity can also be observed in the Body Mass Index (BMI), current use of family planning, contraceptive method, assistance during delivery and intention to use a contraceptive method.

Table 6.4:5 Comparative analysis of Imputed and MDHS-2004 variables

Variable	MDHS-2004		Imputed	
	%	n	%	n
Risk Parity				
Low risk (0-4 children)	69.4	7,189	73.1	1,728
High risk (5 + children)	30.6	3,164	26.9	636
Total	100	10,353	100	2,364
BMI (Body Mass Index)				
Underweight (BMI< 18.5)	7.4	728	7.5	168
Healthy weight (BMI >18.5 &<24.9)	77.6	7,599	77.4	1,729
overweight (BMI>25 &<29.9)	12.4	1,213	12.1	270
Obesity (BMI >30)	2.6	258	3.0	67
Total	100	9,798	100	2,234
Current use of a contraceptive method				
not using	72.2	7,473	72.3	1,708
Using	27.8	2,880	27.8	656
Total	100	10,353	100	2,364
Contraceptive method				
not using	72.2	7,473	72.3	1,708
pill/IUD/Norplant	2.2	228	2.3	55
Injections	15.0	1,550	15.6	368
Condom	1.7	173	2.0	48
Female sterilization	5.1	528	4.4	105
Other	3.9	401	3.4	80
Total	100	10,353	100	2,364
Assistance during delivery				
doctor/nurse/midwife	57.0	4,084	65.9	942
traditional birth attendant	25.6	1,833	19.2	275
Other relatives or friends	17.5	1,251	14.9	213
Total	100	7,168	100	1,430
Intention to use a contraceptive method				
Using modern method	24.0	2,481	24.4	576
Using traditional method	3.9	399	3.4	80
non-user intend to	50.5	5,226	52.3	1,237
non-user does not intend to	21.7	2,247	19.9	471
Total	100	10,353	100	2,364

6.5 Discussion of results obtained from statistical matching

This paper has discussed the application of statistical matching to produce joint information on disability and parity, variables not jointly observed. The statistical matching procedure consisted of data harmonisation, selection and calibration of the matching variables, imputation of variables of interest through constrained nearest neighbour hot-deck and assessment of the accuracy of the outcome data. However, before analysing the link it derived the disability index. In modelling the disability index, the results have demonstrated that all the 16 items of the health domains focused on discriminating people with functioning difficulties. The 16 items focused on people with functioning difficulties because the World Health Survey aimed at identifying people with significant difficulties in carrying out their daily activities (WHO and World Bank Group, 2011). Persons with functioning difficulties were also of interest because functioning difficulties are closely linked to the demand for long-term care (Lafortune and Balestat, 2007). Identification of people experiencing functioning difficulties is also relevant for the development of policies on prevention and rehabilitation (Mitra and Sambamoorthi, 2014).

Apart from distinctly separating persons with disabilities from those without a disability, the IRT RSM results also demonstrated that the functioning difficulty measurement scale reliably measures disability, with an associated R-value of $r= 0.96$. These findings are among the first to demonstrate the reliability of the eight health domains of the World Health Survey in measuring disability in a poorly resourced country like Malawi. These findings also support the assertion by Dr Üstün (2003) and Witvliet (2014) that the eight health domains of the World Health Survey are cross-culturally adaptable. Nonetheless, a comparative analysis of the expected versus observed scores of the test characteristic curve demonstrated that there is a difference between the theta levels of the expected and observed scores. An explanation of this observation is that under item response theory, the focus is on whether or not the participants got each of the individual item responses correct, rather than on the raw measurement scores (Baker and Kim, 2017). Therefore, the difference in theta levels, between the observed and the expected scores, could be due to the individual items of the measurement scale, and not to the aggregate value of the item response scores.

The pairwise association measures used for selecting matching variables have illustrated that age is a significant predictor of both disability and parity even though it does not meaningfully explain the variation in disability. Age could not comprehensively explain the variation in disability in this

study because of the complex relationship between age and self-reported disability. According to Jylhä et al (2009) age weakens the relationship between functional limitations and self-health assessment. This implies that as age of participant increases the probability of reporting a functional limitation (disability) may stay the same as that of young people even if the health status indicates a worsening state (Jylhä *et al.*, 2001; Jylhä, 2009).

The Chi-square results also demonstrated that level of education and marital status had a weak relationship with parity, (or) the number of children born to a woman. This study finding contradicts the fertility theory that states that education improves women's autonomy, that is the ability to make their own decisions with regard to child care and family planning methods which can in turn result in fewer children (Cleland and Van Ginneken, 1988; Basu and Stephenson, 2005). The result supports Jejeebhoy (1995) findings, that socio-economic development and the situation of women in traditional kinship structures affect the relationship between education and the number of children born to a woman (Jejeebhoy, 1995). In the case of Malawi, the poor socio-economic development of the country and the desire for children as social security, help explain the weak relationship between the level of education and parity (Caldwell and Caldwell, 1987; Jejeebhoy, 1995; NSO, 2009).

Harmonisation of the datasets through reclassification of the matching variables, assessment of missing values and examination of the distribution pattern of matching variables through dissimilarity or similarity measures, assisted in the computation of representative imputed values. This process of data harmonization has not only been recommended as the first stage in statistical matching but has also been found to play a critical role in situations where there is lack of consistency in the wording of similar questions in social surveys (D'Orazio, Di Zio and Scanu, 2006; Leulescu and Agafitei, 2013; Donatiello *et al.*, 2014). For example, in statistical matching of the European Statistics on Income and Living conditions (EU-SILC) and the Household Budget Survey (HBS), Danietiello et al (2014) found harmonizing of the common variables in the two datasets improved the final estimations of household income, consumption and wealth (Donatiello *et al.*, 2014).

The statistical matching of the MWHS-2003 and the MDHS-2004 using the constrained nearest neighbour hot-deck method, demonstrates that the procedure preserve the marginal distribution of the variables after imputation, as shown by the dissimilarity and similarity indexes that were computed after the statistical matching procedure. These results correspond to the Leulescue et al (2013) study, where the hot-deck method preserved the marginal distribution of life satisfaction, trust in institutions and social exclusion variables, before and after imputation. Donatello et al (2014), also found the use of the hot-deck method to produce satisfactory results

even though they are associated with high levels of uncertainty (more than 5%) (Donatiello *et al.*, 2014).

The main limitation of this study is the use of old datasets (MWHS-2003and MDHS-2004) whose information may be slightly different from the present condition. Nonetheless, the MWHS-2003 dataset is the most useful data that contains comparative individual level disability data on Malawian people. The other limitation is the age group of the MDHS-2004 sample, which has limited the synthetic data to persons of the reproductive, ages (18-49). The level of disability in this age group is comparatively lower than that of women aged 60 and above. Nevertheless, the age group 18 to 49 is more likely to access sexual and reproductive health services than those members of the population aged 60 and above. Thus, the results drawn from this dataset is sufficient for policy development.

6.6   Conclusion of statistical matching outcomes

It can be concluded from this statistical matching procedure, that the matching procedure provides good data for measuring the sexual and reproductive behaviour of marginalised and resource-constrained populations, and in situations where the variables of interest have not been jointly observed. The data obtained from the matching procedure are also valid and reliable as shown by the similarity of the marginal distribution of the imputed variables and the donor dataset (MDHS-2004). Nonetheless, there is a need for harmonisation of the common variables in population surveys to improve accuracy and consistency of the integrated datasets, since they play a critical role in the matching procedure. The data obtained from this statistical matching procedure has been used to examine the link between disability measurement and access to sexual and reproductive health, in chapter 7

7 Chapter 7: Examining the relationship between functional measures of disability and uptake of sexual and reproductive health services in Malawi

7.1 Introduction

This chapter discusses the relationship between impairment and functional measures of disability and the uptake of Sexual and Reproductive Health (SRH) services in Malawi. Research elsewhere on the measurement of disability in low-income countries has demonstrated that the approaches used in measuring disability either overestimate or underestimate the proportion of persons with disabilities (Mont, 2007a; WHO and World Bank Group, 2011). For example, impairment measures of disability have been found to produce disability estimates that are below 3% (United Nations, 1990; Mbogoni, 2003). Despite disability measures overestimating or underestimating the proportion of persons with disability, they have still been found to be helpful in providing input for the development of policies and programmes on health service provision (Mont, 2007a; Palmer and Harley, 2012). For example, the World Health Organization's 2000 Global Burden of Disease study used Disability Adjusted Life Years (DALYs) to show that mental and neurological disorders were contributing to 30.8% of all years of health life lost to disability (Leonardi *et al.*, 2005). This information was then used as a justification for the Global Campaign against headache disorders. Nevertheless, such kind of studies are rare in the Sub-Saharan African context, let alone in Malawi, where measurement of disability has only been considered from the perspective of estimating the number of persons with an impairment as discussed in section 1.2 of the introductory chapter. Building on this base, in this chapter we investigate the association between functional measures of disability as well as the resulting uptake of sexual and reproductive health services in Malawi.

The association between disability measures and the uptake of SRH services has also been conducted with a view that little has been done to examine this relationship, thus affecting the current development of policies and programmes on the sexual and reproductive health of persons with disabilities in Malawi. There are also data issues in terms of disability information that are mostly the result of how disability is conceptualised and how this conceptualization affects the prioritization of disability information collected during population censuses and surveys. To address this data limitation issues chapter six has provided a detailed analysis of statistically matching two different datasets. In the analyses presented in this chapter, the data

was obtained from statistically matching the 2003 Malawi World Health survey (MWHS-2003) and the 2004 Malawi Demographic and Health survey (MDHS-2004). The 2004 Malawi Demographic and Health survey collected most of its information on sexual and

Before discussing the link between measures of disability and uptake of sexual and reproductive health services, this chapter discusses the sources of data and analytical models used to examine the link between measures of disability and sexual and reproductive health services. Further to the discussion of the analytical models, the chapter examines the background characteristics of the sampled population.

7.2 Methods and data for examining the link between disability measurement and access to SRH services

7.2.1 Data used to examine the relationship between measures of disability and SRH services

The data used to examine the relationship between impairment and functional measures of disability and SRH services were obtained by statistically matching the MWHS- and the MDHS-2004. Statistical matching is a statistical technique for combining information from two distinct data sources that refer to the same target population (D'Orazio, 2011).The MWHS-2003 and the MDHS-2004 were statistically matched because of the limited availability of data on the sexual and reproductive health behaviour of persons with disabilities in Malawi. In statistically matching the two datasets, it was assumed that the surveys are distinct but were collected from the same population in Malawi (D'Orazio, Di Zio and Scanu, 2010; D'Orazio, 2016). Statistical matching of the datasets was also based on the assumption that there exists no auxiliary information on the statistical relationship between disability and parity (variables used in the matching process). This means that the statistical matching of the two datasets was performed under the *Conditional Independence Assumption* (CIA) (D'Orazio, 2011). The matching procedure was also performed with a view of exploring uncertainty due to the absence of joint information on the disability index and the parity variable. To ensure that the resulting dataset is of good quality, the marginal distributions of the common variables found in the two datasets (i.e. place of residence, age, level of education and marital status) were compared and harmonised. A detailed description of the statistical matching procedure is provided in chapter 6.0.

7.2.1.1 2003 Malawi World Health Survey (MWHS-2003)

The 2003 Malawi World Health Survey is a nationally representative survey that was developed by the World Health Organization and was conducted in 2003. The survey was developed with the aim of providing reliable and comparable information on health systems (World Health

Organization, 2003; Witvliet, 2014). The survey collected comprehensive information on population health that provided an overview of how health systems are functioning for purposes of policy analysis. The topics covered during the survey included health status, health care, health conditions such as heart diseases and general demographics. The 2003 Malawi World Health Survey targeted men and women aged 18 years and over and collected information from 5, 297 participants (World Health Organization, 2003). In this chapter, the 2003 Malawi World Health Survey has been used because it is one of the few health surveys in the country that contains standardized self-reported health data that is comparable across nations (Witvliet, 2014).

7.2.1.2   2004 Malawi Demographic and Health Survey (MDHS-2004).

The MDHS-2004is a cross-sectional survey that was conducted in Malawi in 2004. This survey was developed by the Malawi National Statistics Office with the aim of providing information on " family planning and fertility behaviours of the Malawian population and thereby enable policymakers to evaluate and enhance family planning initiatives in the country" (NSO, 2005). The MDHS-2004 was also built around the DHS questionnaire template. Some of the information collected during the survey included fertility levels, awareness and use of family planning methods, use of maternal and child health services, and knowledge and behaviours related to HIV and other sexually transmitted infections. The MDHS-2004 targeted women and men aged 15-49 and 15-54 respectively. In total it collected information from 11,698 women and 3,261 men (NSO, 2005). In this study, the MDHS-2004 has been used because it was conducted at a period that is close to the 2003 Malawi World Health Survey. It is assumed that the characteristics of the population sampled in this survey were similar to those sampled in the 2003 Malawi World Health Survey as demonstrated in table 6.3:1 of chapter 6

7.2.2   Study variables

There are a number of sexual and reproductive health services that are provided at public health facilities in Malawi , including family planning, maternal and child health services, abortion, treatment and prevention of sexually transmitted infection including HIV (Glasier *et al.*, 2006; UNFPA, 2014). To examine the relationship between impairment and functional measures of disability and uptake of sexual and reproductive health services in Malawi, this study focuses on use of modern contraceptive methods, assistance during delivery, place of delivery and HIV counselling services during ante-natal visits. The study focuses on these services because literature suggest that they are the services where most women with disabilities experience stigma and discrimination due to attitudinal, health care systems and non-inclusive policies

(Becker, Stuifbergen and Tinkle, 1997; Wazakili, Mpofu and Devlieger, 2006; WHO and UNFPA, 2009). In addition to stigma and discrimination, the services also save the life of the woman and the child and improves the well-being of the household and overall populations (Glasier *et al.*, 2006; UNFPA, 2014).

Current use of contraceptive methods, assistance during delivery, place of delivery and HIV counselling will be the dependent variables for this study. The main independent variables will be presence or absence of an impairment and a functioning (or disability) index. Research on the utilization of sexual and reproductive health services among women with disabilities has indicated that individual factors such as economic status and environmental factors such as place of residence, influence women's access to sexual and reproductive health services (Smith *et al.*, 2004; Ahumuza *et al.*, 2014; Lee *et al.*, 2015). Therefore, to control for the effect of individual and environmental factors on access, the economic status of the women as measured by a wealth index, age, education, marital status and place of residence are used as control variables.

7.2.2.1   Deriving dependent variables

Current use of a contraceptive method

During the MDHS-2004 women, aged 15 to 49 years were asked if they were currently doing something or using any method to delay or avoid getting pregnant. Women who responded positively to this question were further requested to mention the kind of method that they were currently using. This question had options like female sterilization, male sterilization, pill, IUD, injectable, implants, condom, female condom, periodic abstinence, withdrawal and 'other'. The *current use of contraceptive methods* variable used in this chapter has been grouped into two categories, using and not using modern contraceptive method. The contraceptive use variable has been reduced to two categories because there was a small number of women who were using each different type of family planning method.

Assistance during delivery

The variable *assistance during delivery* was derived from the Demographic and Health Survey question: "Who assisted with the delivery of (Name)?", (NSO, 2005). Responses included; health professional doctor or clinical officer; nurse or midwife; patient attendant or another person; traditional birth attendant; relative or friend; and other. In this chapter, the variable assistance at delivery has been categorised as: (i) doctor or nurse or midwife; (ii) traditional birth attendant; (iii) other relative or friend. The variable has been grouped into three categories because there were small or no cases in some of the categories, particularly the category for doctor, patient attendant and others.

Place of delivery

 The variable place of delivery was derived from the 2003 Malawi World Health Survey. In the 2003, Malawi World Health Survey women who had given birth within the last 2 years before the survey were asked to explain where they had given birth. In responding to this question, women gave answers that included hospital or maternity home, other health facilities, at home and on the street or market. In the 2004 Demographic and Health Survey, women were also asked to provide information on where they had given birth to their last three children before the survey. Responses to this question included at home, at a public sector hospital or facility, mission hospital, traditional birth attendant and other places. This study only focuses on the birth given 2 years prior to the survey to reduce errors that may occur due to recall issues.

HIV Counselling

This study also examines whether a woman has ever been offered HIV counselling services during her antenatal visits. This variable is vital in this study because of the attitude and misconception that people have towards persons with disabilities. Research in both developed and developing countries has demonstrated that most societies hold the misconception that persons with disabilities are asexual beings (that is to say, they do not indulge in sexual activities). This misconception has led to the belief that persons with disabilities do not acquire the HIV-virus (Becker, Stuifbergen and Tinkle, 1997; Wazakili, Mpofu and Devlieger, 2006; WHO and UNFPA, 2009) . Furthermore, in sub-Saharan African countries, Malawi included, there are beliefs that if you are HIV positive and you sleep with a person with a disability you can get cured of the virus (Munthali, Mvula and Ali, 2004; Ahumuza *et al.*, 2014). In Malawi, this misconception is premised on the understanding that persons with a disability are pure, meaning that they are free from diseases and as such they can act as a cleanser of the HIV virus (Mji et al 2008). Such misconceptions and beliefs that are held by community members in the sub-Saharan region increase the risk of acquiring an HIV virus by persons with disabilities. Therefore, it is important to assess whether women with disabilities have ever accessed HIV counselling services. The variable *HIV counselling* was derived from the 2003 Malawi World Health Survey where women who had given birth two years prior to the survey were asked the following question; "During your antenatal care visits for your pregnancy with [NAME], were you given any information or counselled about HIV, the virus that causes AIDS?", (World Health Organization, 2003).

7.2.2.2   Deriving disability variables (impairment and functioning variables)

<u>Impairment variable</u>

The impairment variable in this study is derived from interviewer observations of the 2003 Malawi World Health survey. During the data collection process, interviewers were asked to record whether their participant had a hearing or vision problem; used a wheelchair; used a cane or crutches or walker; had difficulties in walking; had a paralysed arm, hands or legs; coughed continually; had shortness of breath; had a mental problem or other health problems; or had an amputation of a limb or part of a limb. A detailed discussion on how this variable was derived in this study is given in section 4.2.3 of chapter 4.

<u>Disability index (functional limitation)</u>

 The disability index variable that is used in this study is also derived from the 2003 Malawi World Health Survey. During the survey, participants were asked to evaluate their state of health during the 30 days prior to the survey. They were asked to evaluate their health status in terms of difficulties that they experienced while performing their daily activities such as moving around or washing. To evaluate their health state, participants were asked to rate their [difficulty in] functioning on a scale of 1 to 5, where 1= none, 2=mild, 3= moderate, 4=severe, 5=extreme or cannot do. Box 7.2:1 provides a summary of the daily activities that the survey participants rated. Box 7.2:1 indicates that survey participants evaluated their functioning in mobility, self-care, pain and discomfort, cognition, Interpersonal activities, vision, sleep and energy and affect. Responses to these eight domains of daily activities were then used to create a functional disability index. A detailed discussion of how the disability index was derived has been given in section 6.3.2 of chapter 6 on data deficiencies in disability measurement.

To present the results on the proportional distribution of women with various levels of functioning by background characteristics, women are categorised depending on the scale of their response. The first category relates to women who reported no difficulty or who reported mild difficulties in all the eight health domains. The second category relates to women who reported at least one moderate difficulty (this category includes women who reported one or more moderate difficulties and no severe or extreme difficulties). The third category relates to women who reported one or more severe or extreme difficulties (regardless of whether they reported moderate difficulties in other items).

Box 7.2:1 Health state description of the 2003 Malawi World Health Survey

Mobility
Q1. Overall, in the last 30 days, how much difficulty did you have with moving around?
Q2. In the last 30 days, how much difficulty did you have in vigorous activities such as running 3km (or equivalent) or cycling?

Self-care
Q1. Overall, in the last 30 days, how much difficulty did you have with self-care, such as washing or dressing yourself?
Q2. In the last 30 days, how much difficulty did you have in taking care of and maintaining your general appearance (e.g. grooming, looking neat and tidy etc.)

Pain and Discomfort
Q1. Overall, in the last 30 days, how much of bodily aches or pains did you have?
Q2. In the last 30 days, how much bodily discomfort did you have?

Cognition
Q1. Overall, in the last 30 days, how much difficulty did you have with concentrating or remembering things?
Q2. In the last 30 days, how much difficulty 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 etc.)?

Interpersonal relationships
Q1. Overall, in the last 30 days, how much difficulty did you have with personal relationships or participation in the community?
Q2. In the last 30 days, how much difficulty did you have in dealing with conflicts and tensions with others?

Vision
Q1. Do you wear glasses or contact lenses?
Q2. In the last 30 days, how much difficulty did you have in seeing and recognizing a person you know across the road (i.e. from a distance of about 20 meters)?
Q3. In the last 30 days, how much difficulty did you have in seeing and recognizing an object at arm's length or in reading?

Sleep and Energy
Q1. Overall, 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?
Q2. In the last 30 days, how much of a problem did you have due to not feeling rested and refreshed during the day (e.g., feeling tired, not having energy)?

Affect
Q1. Overall, in the last 30 days, how much of a problem did you have with feeling sad, low or depressed?
Q2. Overall, in the last 30 days, how much of a problem did you have with worry or anxiety?

Source: 2003 Malawi World Health Survey (World Health Organization, 2003)

7.2.3 Analysing the relationship between disability and sexual and reproductive health services

Tests of associations, namely Chi-square tests, multiple and multinomial logistic regression models have been used in this chapter to examine the relationship between the measures of disability and the uptake of SRH services. A Chi-square test was used to test for the linear relationship between the dependent and independent variables. Multiple and multinomial logistic regressions were used to model the probability of utilizing the SRH services, given that the woman has an impairment or functional limitation. The following paragraphs provide a detailed description of analytical methods used in examining the link between disability measures and uptake of SRH services.

7.2.3.1 Test of association between the dependent and independent variables

To test for association between the dependent variables and the independent variables, this study used the Chi-square test. The Chi-square test is a statistical method that is used to examine the relationship between two categorical variables (Deviant, 2011; McHugh, 2013). In this study, the Chi-square test was used to test the relationship between the dependent variables (current use of contraceptive methods, assistance during delivery, place of delivery and HIV counselling) and the independent variables (impairment and functional limitation variables). The hypothesis underlying the Chi-square test is that the two categorical variables are independent versus the hypothesis that the two categorical variables are dependent (McHugh, 2013). In terms of the output, if the Chi-square test result is small, it indicates that there is no relationship between the two variables (Deviant, 2011). A large Chi-Square test result, on the other hand, indicates that there is a relationship between the two categorical variables. The significance of the relationship between the two variables was tested at the 95% level of significance.

7.2.3.2 Logistic regression model

A logistic regression model is a statistical technique for analysing the relationship between a dichotomous or polychotomous variable of interest and a set of independent or explanatory variables. The procedure of logistic regression is similar to that of linear regression, with the exception that the response variable for the logistic regression is binomial (Sperandei, 2014). In modelling variables using a logistic regression model, the objective is to attempt to model the probability that an event occurs (sometimes referred to as success) to the probability that the event does not occur (referred to failure or the complement of success) (O'Connell, 2006). The result from the modelling procedure is the impact of each variable on the odds ratio of the observed event of interest (Sperandei, 2014). The odds of an event depend on the outcome of success or failure. The odds of an event occurring are greater than 1 when the probability of

success is greater than the probability of failure. When the outcomes of success or failure are equally likely, the odds are 1. The odds of an event are less than 1, when the probability of success is less than the probability of failure.

A logistic regression model has been chosen for this study instead of a linear regression model or a Probit model because the dependent variables of interest in this study are both dichotomous and polychotomous which present problems when modelled using a linear regression. For example, when modelling using linear regressions, there is an assumption of homoscedasticity and normality of errors. Homoscedasticity means that the variance of the predictor variables around the regression line is the same. Normality of errors, on the other hand, means that the error term ε follows a normal distribution with a mean of zero and a constant variance across the independent variables (Hosmer Jr, Lemeshow and Sturdivant, 2013). These two assumptions are violated by a dichotomous dependent variable which is heteroscedastic in nature and has an error term that follows a binomial distribution with probability given by the conditional mean $\pi(x)$ (O'Connell, 2006; Hosmer Jr, Lemeshow and Sturdivant, 2013).

Multiple logistic regression models

 In modelling the relationship between disability and utilization of sexual and reproductive health services, multiple logistic and the multinomial logistic regression models were used. Multiple logistic regressions were used to estimate the relationship between disability measures and contraceptive use, place of delivery and HIV counselling. Contraceptive use, place of delivery and HIV counselling are variables with two responses, yes or no. This means that they have binary responses of 1=yes and 0=no. Modelling the contraceptive use variable we are estimating the probability of using a contraceptive method (Y=1) given a set of independent variables including absence or presence of an impairment and difficulties in functioning. In notation terms this is the estimate;

$Pr\big(Y = 1|X_1, X_2,..., X_P\big) = \pi(x)$. The specific form of the multiple logistic regression models is

$$In(Y') = logit[\pi(x)] = In\left(\frac{\pi(x)}{1-\pi(x)}\right) = \beta_0 + \beta_1 X_1 + \beta_2 X_2 + \cdots \beta_p X_p \qquad (7.1)$$

(O'Connell, 2006)

Where:

Y' Refers to the (log of the) odds of Y=1

β_0 and β_i are regression parameters, where β_0 is the intercept and β_i is the slope for each independent variable

X_i where ì=1,2,…,p are the explanatory variables, which in this case are impairment, functional limitation index, age, education, wealth index or income index, marital status, and place of residence.

Multinomial Logistic regression model

For the variable *assistance during delivery*, its relationship with impairment and functional limitation index was modelled using multinomial logistic regression. Multinomial logistic regression is an extension of the binary logistic regression. It models variables that have three or more categories which are not ordered (O'Connell, 2006; Hosmer Jr, Lemeshow and Sturdivant, 2013). Multinomial logistic regression has been chosen in this study because the variable assistance during delivery has more than two response categories that are not ordered. The variable assistance during delivery has three responses which are; 0= doctor/nurse /midwife; 1=traditional birth attendant; 2=other relatives or friends. In modelling the variable on assistance during delivery using multinomial logistic regression, there is an attempt to estimate the probability of a woman being assisted by each of the three groups of assistance, as well as to estimate the odds of the chosen category as a function of explanatory variables (Hosmer Jr, Lemeshow and Sturdivant, 2013).

When modelling a polychotomous variable using multinomial logistic regression, the outcome variable or dependent variable is split into multiple dummy variables coded 1 and 0. For a three categorical variables, the variable is coded as follows; if Y=0 then $Y_0=1$, $Y_1=0$ and $Y_2=0$; if Y=1 then $Y_0=0$, $Y_1=1$ and $Y_2=0$; and if Y=2, then $Y_0=0$, $Y_1=0$ and $Y_2=1$. However, not all categories are coded into dummy variables; one category is left to be used as a reference category. Thus, for a variable with K categories, k-1 categories are created and each category is estimated as a separate binary logistic regression model. Thus, the probability of success is modelled in that category in comparison to the reference category (Hosmer Jr, Lemeshow and Sturdivant, 2013). Mathematically, for the variable assistance during delivery where assistance by doctor/nurse/midwife is the reference category, the modelling probability is;

$$Pr(Y = 1|X) = In\left[\frac{Pr(Y=1|X)}{Pr(Y=0|X)}\right] = \beta_{10} + \beta_{11}x_1 + \beta_{12}x_2 + \cdots + \beta_{1p}x_p \qquad (7.2)$$

And

$$Pr(Y = 2|X) = In\left[\frac{Pr(Y=2|X)}{Pr(Y=0|X)}\right] = \beta_{20} + \beta_{21}x_1 + \beta_{22}x_2 + \cdots + \beta_{2p}x_p \qquad (7.3)$$

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Where,

Pr(Y=0|X) is the reference category and is the probability of being assisted by a doctor/nurse/midwife given a set of explanatory variables.

$\frac{Pr(Y=1|X)}{Pr(Y=0|X)}$ Is the probability of being assisted by a traditional birth attendant in comparison to being assisted by a doctor/nurse/midwife given a set of explanatory variables

$\frac{Pr(Y=2|X)}{Pr(Y=0|X)}$ Is the probability of being assisted by other relatives or friends in comparison to being assisted by a doctor/nurse/midwife given a set of explanatory variables

The output from both multiple logistic regression and multinomial regression can be interpreted based on odds ratios or probabilities. A probability is "the ratio between a number of events favourable to some outcome variable divided by a total number of events" (Sperandei, 2014). An odds ratio, on the other hand, is the ratio between the odds. Odds are the ratio between the likelihood that an event will occur against the likelihood that an event to a particular dependent variable will not occur. When an odds ratio is greater than 1, it indicates that the dependent variable has an effect on the odds of success.

Interactions with logistic regression

Further to the modelling of the dependent variables with the independent variables, the study also included interaction terms in the logistic regression models. An interaction term can be described as a synergistic or multiplicative effect that is tested by a adding a product variable XZ to the model (Newsom *et al.*, 2003). An interaction term is often included in the logistics regression model when it is assumed that the relationship between one predictor X, and the outcome or response variable, Y, depends on the value of another independent variable Z (Jaccard, 2001; Newsom *et al.*, 2003). Thus Z is perceived as the moderator of the effect of X on Y. However, the X Z interaction can in some cases also be interpreted as the effect of Z on Y is moderated by X.

A logistic regression model with an interaction term is mathematically written as;

$$In\left(\frac{\pi}{1-\pi}\right) = \alpha + \beta_1 X + \beta_2 Z + \beta_3 XZ \qquad (7.4)$$

Where: XZ is the interaction term and

β_3 is the coefficient of the interaction term.

If the coefficient of the interaction term is significant, the conclusion is that the association between X and the probability that Y=1 depends on the values of Z (Newsom *et al.*, 2003).

With regards to this study, an interaction term or effect was added to the logistic models to test the multiplicative effect of having an impairment and functional limitations in carrying out daily activities. Research on access to sexual and reproductive health services among women with disabilities has indicated that women with physical or intellectual impairments who experience severe functional limitations are less likely to access sexual and reproductive services such as antenatal services compared to those with impairments only(Smith *et al.*, 2004; Iezzoni *et al.*, 2014; Tanabe *et al.*, 2015) . This study therefore aimed to examine this assertion by interacting presence of an impairment with the level of functional limitation.

7.3   Results from the analysis of the relationship between measures of disability and SRH services

7.3.1   Demographic characteristics of the participants

To assess the relationship between impairment and functional measures of disability and uptake of sexual and reproductive health services the study first examined the demographic characteristics of women with and without an impairment and those with various levels of functional limitation, as shown in table 7.3:1 and table 7.3:2.

Presence of an impairment by background characteristics

Table 7.3:1 presents the demographic characteristics of women with and without an impairment. The results in the table illustrate that 3.8% of the sampled women were observed to have an impairment whilst 96.2% had no impairment. Examining the women with impairment by age group, table 7.3:1 indicates that a high proportion of women with impairment (49%) are aged between 35 and 49 years, followed by women in the age range 25-34 whose proportional distribution is 30.7%. Women aged between 18 and 24 have the lowest proportion of impairment (20.3%) compared to the other age groups. In order to assess whether the relationship between age and impairment is statistically significant at the 95% level of significance a Chi-square test is used. The results in table 7.3:1 indicate that the relationship between age and presence of an impairment is statistically significant with an associated P-value of p=0.01

With regards to place of residence, the results in table 7.3:1 indicates that a high proportion of women with an impairment (71.3 %) reside in the rural areas compared to those in the urban

areas (28.7%). However, the relationship between place of residence and presence of an impairment is not statistically significant at the 95% level of significance.

Table 7.3:1 further indicates that a high proportion of women with impairments (54.8%) are married or cohabiting. Nonetheless, this percentage is less than the percentage of women without impairments who are married or cohabiting (75%). Table 7.3:1 also indicates that more than a quarter of women with impairments are separated or divorced compared to women without impairments (25.7% versus 11.4%). The relationship between presence of an impairment and the marital status of a woman is statistically significant at the 95% level of significance.

With regards to wealth or economic status, table 7.3:1 indicates that a high proportion of women with an impairment are in the two lowest wealth quintiles (29.1% and 20.6%) compared to women without impairments whose proportional distribution is 19.4% and 18.3% respectively in these two quintiles. Nevertheless, the association between the presence of an impairment and a woman's economic status is not statistically significant at the 95% level of significance. Concerning the association between having an impairment and functional limitation, the results in table 7.3:1 indicate that the relationship is statistically significant, and that people with impairments have high levels of severe functional limitation compared to those with no impairments (41.8% to 10.7% respectively).

Table 7.3:1 Percent distribution of women aged 18 to 49 years by presence of an impairment according to background characteristics (Malawi 2003)

Background characteristics	Impairment				
	No impairment	Has an impairment	Total	Number	(P-value)
Age group					P = 0.01
18-24	39.2	20.3	38.4	947	
25-34	35.2	30.7	35.1	880	
35-49	25.6	49.0	26.5	538	
Total	100	100	100	2,365	
Place of residence					P = 0.37
Urban	17.4	28.7	17.8	432	
Rural	82.6	71.3	82.2	1,933	
Total	100	100	100	2,365	
Level of education					P = 0.07
No education	24.7	21.1	24.6	483	
Less than Primary	52.4	60.9	52.7	1,284	
Primary completed	18.1	3.4	17.6	477	
Secondary and above	4.8	14.6	5.1	121	
Total	100	100	100	2,365	
Marital status					P = 0.01
Never Married	9.5	16.2	9.8	195	
Married or Cohabiting	75.0	54.8	74.2	1,718	
Separated or divorced	11.4	25.7	12.0	316	
Widowed	4.1	3.2	4.1	136	
Total	100	100	100	2,365	
Wealth index					P = 0.60
Lowest	19.4	29.1	19.8	526	
Second	18.3	20.6	18.4	459	
Middle	21.6	17.1	21.4	465	
Fourth	20.0	18.6	20.0	463	
Highest	20.7	14.7	20.5	452	
Total	100	100	100		
Functional limitation					
No functional limitation	79.7	34.6	78.0	1,903	P=0.00
At least one moderate limitation	9.6	23.6	10.2	227	
At least one severe or extreme limitation	10.7	41.8	11.9	235	
Total	100	100	100		
Number	2285 (96.2%)	80 (3.8%)		2,365	

[3]Source: MWHS-2003

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[3]

Functional limitation by background characteristics

In addition to the presence of an impairment, the study also examined the proportional distribution of women with various levels of functional limitations. The functional levels included no functional limitations, at least one moderate limitation and at least one severe or extreme level of functional limitation. Table 7.3:2 presents the distribution of the women with various levels of functional limitation according to their background characteristics. The table indicates that 78% of the women reported to have no functional limitation whilst 10.2% reported to have at least one moderate limitation and 11.8% reported to have at least one severe or extreme limitation.

Examining the reported functional limitation by age, table 7.3:2 shows that a high proportion of women in the age group 35 to 49 reported having experienced moderate difficulties (36.3% and severe or extreme difficulties (31.9) in carrying out their daily activities during the 30 days before the survey. Women aged between 18 and 24 were the least likely to report moderate difficulties (24.7%) but reported high levels of severe or extreme difficulties (35.2%) in carrying out their daily activities compared to the other age-groups. The reported functional difficulties by age was statistically significant at the 95% level of significance with an associated P-value of p=0.00.

With regards to marital status, table 7.3:2 demonstrates that married or cohabiting women reported experiencing moderate difficulties (72.5%) in carrying out their daily activities compared to the never married, widowed or separated or divorced women (7.1%, 6.7% and 13.7% respectively). Married or cohabiting women also reported high levels of severe or extreme limitations (65.8%) in carrying out their daily activities compared to the never married, separated or divorced, or widowed women (11.7%,18.2% and 4.3% respectively).

Concerning the economic status of women, table 7.3:2 indicates that women in the highest wealth quintile reported more experiences of severe or extreme levels of difficulty in carrying out their daily activities compared to women in the four lower levels of the wealth quintile (16.4%, 11.6%, 19.6% and 19.1% respectively). With regards to moderate levels of difficulty, table 7.3:2 indicates that a high proportion (23.5%) of women in the middle wealth quintile reported having experienced moderate levels of functioning difficulties compared to the women of the highest wealth quintile (17.1%%). The difference in the reported functional limitations by economic status is statistically significant at the 95% level of significant with an associated P-value of p=0.04.

Table 7.3:2 **Percent distribution of women aged 18 to 49 by functional status by background characteristics (Malawi 2003)**

Background	Functional limitation			Total	Number	Chi-square test (P-value)
	No functional limitation	One moderate limitation	at least one severe or extreme limitation			
Age group						P = 0.00
18-24	40.5	24.7	35.2	38.3	947	
25-34	35.0	39.1	32.9	35.2	880	
35-49	24.4	36.3	31.9	26.5	538	
Total	100	100	100	100	2,365	
Place of residence						P = 0.41
Urban	17.5	22.4	14.8	17.7	432	
Rural	82.5	77.6	85.2	82.3	1,933	
Total	100	100	100	100	2,365	
Level of education						P = 0.45
No education	23.8	29.0	26.3	24.7	483	
Less than Primary	52.6	54.3	51.6	52.7	1,284	
Primary completed	18.6	12.5	15.2	17.6	477	
Secondary and above	4.9	4.2	7.0	5.1	121	
Total	100	100	100	100	2,365	
Marital status						P = 0.05
Never Married	9.9	7.1	11.7	9.8	195	
Married or Cohabiting	75.7	72.5	65.8	74.2	1,718	
Separated or divorced	10.8	13.7	18.2	11.9	316	
Widowed	3.7	6.7	4.3	4.1	136	
Total	100	100	100	100	2,365	
Wealth quintile						P = 0.04
Lowest	19.9	22.6	16.4	19.8	526	
Second	19.0	21.1	11.6	18.3	459	
Middle	21.3	23.5	19.6	21.3	465	
Fourth	20.8	15.8	19.1	20.0	463	
Highest	19.1	17.1	33.3	20.6	452	
Total	100	100	100	100		
Number	1,903(78%)	227(10.2%)	235 (11.9%)		2,365	

[4]Source: MWHS-2003

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7.3.2   Test of association between dependent and independent variables

In addition to examining the background characteristics of the survey participants, the study also examined the relationship between impairment and functional measures of disability and the sexual and reproductive health services. Table 7.3:3 and 7.3:4 presents results on the test of association between the disability variables and sexual and reproductive health variables.

Association between impairment and SRH services

Table 7.3:3 presents the results obtained from the cross tabulations and test of association between the impairment variable and contraceptive use, HIV counselling, place of delivery and assistance during delivery variables. The results in table 7.3:3 indicate that the proportion of women with impairments (74.8%) who were not currently using any modern contraceptive method was not different from the proportion of women without impairments (73.3%). The table further indicates that the proportion of women with impairments (25.2%) who were currently using modern contraceptive methods was slightly lower than that of women without impairments (26.7%). However, the association between contraceptive use and impairment is not significant at the 95% level of significance. It should be pointed out, however, that overall, contraceptive use is quite low.

Table 7.3:3 further indicates that 44.1% of women with impairments were offered counselling services about the HIV virus during their antenatal visits compared to women without impairments (48.6%). The association between accessing HIV counselling services and impairment is not statistically significant at the 95% level of significance. Concerning place of delivery, table7.3:3 indicates that among women with an impairment 36% gave birth at home whilst 64% gave birth at a public health facility. The proportion of women with impairments giving birth at a health facility is lower compared to that of women without impairments but the relationship is not statistically significant.

With regards to professional health assistance during delivery, table 7.3:3 indicates that more than a quarter of women with impairments were assisted by a traditional birth attendant compared to 24.7% of women without impairments. A high proportion of women with impairments were also assisted by a friend or relative during their childbirth compared to women without impairments (17.3% compared to 14.8% respectively), but the relationship is not statistically significant.

Table 7.3:3 Percent distribution of women aged 18 to 49 by impairment and Sexual and Reproductive Health services (Malawi 2003)

Sexual and Reproductive Health services	Impairment				Chi-square test (P-value)
	No Impairment	Has an impairment	Total	Number	
Current contraceptive use					P=0.85
Not currently using	73.3	74.8	73.3	1,716	
Currently using	26.7	25.2	26.7	649	
Total	100	100	100	2,365	
HIV counselling					P = 0.78
Not counselled	51.4	55.9	51.5	888	
Counselled	48.6	44.1	48.5	556	
Total	100	100	100	1,444	
Place of delivery					P = 0.47
At Home	28.6	36.0	28.7	387	
Hospital facility	71.4	64.0	71.3	1,057	
Total	100	100	100	1,444	
Assistance during delivery					P = 0.83
Doctor/Nurse/Midwife	60.5	55.3	60.4	942	
Traditional birth attendant	24.7	27.4	24.8	276	
Other relative or friend	14.8	17.3	14.9	226	
Total	100	100	100	1,444	

Association between functional disability and SRH services

Table 7.3:4 presents results obtained from cross tabulating and testing the association between functional measures of disability and sexual and reproductive health services. The results in the table indicate that among women with at least one moderate limitations 31.8% were currently using modern contraceptive methods whilst 68.2% were not currently using any contraceptive methods. Concerning women with at least one severe or extreme level of functional limitation, 27.3% were currently using modern contraceptive methods whilst 72.7% were not using any modern contraceptive methods. The proportion of women using modern contraceptive methods among those with moderate or severe levels of functional limitations is higher compared to that of women with no functional limitation. However, the association between functional limitation and use of modern contraceptive methods is not significant at the 95% level of significance.

Table 7.3:4 further indicates that among women aged 18 to 49, who had given birth in the last two years before the survey, with at least one severe or extreme levels of functioning difficulty, only 28.5% were counselled about the HIV virus compared to 44.1% of women with moderate difficulties and 51.5% of women with no functional limitation. The relationship between functional limitation and HIV counselling during antenatal visits is statistically significant at the 95% level of significant with an associated p-value of <0.001.

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With regards to place of delivery, table 7.3:4 indicates that more than a third of women with moderate difficulties and those with severe or extreme levels of functioning difficulties gave birth at home compared to 27.5% of women with no functional limitation. Concerning hospital deliveries, table 7.3:4 indicates that more than 70% of women with no functional limitation gave birth at a health facility compared to women with moderate or severe levels of functioning difficulties (67.6% and 65.9% respectively) but not statistically significant.

Concerning professional assistance during delivery, table 7.3:4 indicates that a doctor, nurse, or midwife assisted 62% of women with no functional limitations compared to women with moderate limitations 55.9% and severe or extreme levels of difficulty 51.9%. Traditional birth attendants on the other hand, assisted more than a quarter (29.2%) of women with severe levels of functional limitations and 25.7% of women with moderate levels of functioning compared to 24% of women with no functional limitation. However the association between professional health assistance during child-birth and functional limitation is statistically significant.

Table 7.3:4 Percent distribution of women by functional limitation and Sexual and Reproductive Health services (Malawi, 2003)

Sexual and Reproductive Health service	No functional limitation	One moderate limitation	at least one severe or extreme limitation	Total	Number	Chi-square test (P-value)
	Functional limitation					
Current contraceptive use						P = 0.44
Not currently using	74.0	68.2	72.7	73.3	1,716	
Currently using	26.0	31.8	27.3	26.8	649	
Total	100	100	100	100	2,365	
HIV counselling						P = 0.00
Not counselled	48.5	55.9	71.5	51.7	888	
Counselled	51.5	44.1	28.5	48.3	556	
Total	100	100	100	100	1,444	
Place of delivery						P = 0.19
At Home	27.5	32.4	34.1	28.7	387	
Hospital facility	72.5	67.6	65.9	71.3	1,057	
Total	100.0	100.0	100.0	100.0	1,444	
Assistance during delivery						P = 0.37
Doctor/Nurse/Midwife	62.0	55.9	51.9	60.3	942	
Traditional birth attendant	24.0	25.7	29.2	24.8	276	
Other relative or friend	14.0	18.4	18.9	15.0	226	
Total	100	100	100	100	1,444	
Number	1,903	227	221			

7.3.3   Multiple Logistic regression

Further to the assessment of the relationship between the measures of disability and sexual and reproductive health service variables, the study examined the variation in use of the SRH services among women with functional limitations and impairments using logistic regression models. Table 7.3:5 to table 7.3:8 present the results obtained from regressing the measures of disability and modern contraceptive use, HIV counselling, place of delivery and professional health assistance during delivery. Each table presents two regression models. The first model presents the analytical results with functional limitation only and the second model presents results with functional limitation and impairment.

7.3.3.1   Current Contraceptive use

An assessment of the variation in use of modern contraceptive methods among women with functional limitations in model 1 of the regression table 7.3:5 indicates that when we control for a woman's age, wealth status, level of education and marital status, a unit increase in level of functional limitation is not significantly associated with the use of modern contraceptives. The non-significant association continues to be observed even if we include presence of an impairment in the model as shown in model 2 of table 7.3:5.

The second model in table 7.3:5 further indicates that there is no significant association between having an impairment and using modern contraceptives, even though women with an impairment have the lower odds of using modern contraceptive methods by a factor of (Odds ratio=0.74).

With regards to the control variables (age, wealth status, level of education and marital status), both the model with functional limitation only and the one with functional limitations and impairment, indicates that age of the woman, level of education and marital status are significantly associated with the use of modern contraceptive methods. A unit increase in age increases the use of modern contraceptive methods by 2% when all the other variables in the model are held constant.

The level of education of a woman is also significantly associated with a woman's use of modern contraceptive methods, but the association is more pronounced among women with less than primary education. Women with less than primary education are 55% more likely to use modern contraceptive methods compared to women with no education when all the variables in the model are held constant. Being married or cohabiting also increases the odds ratio of using modern contraceptive methods by 93% compared to being single. Women who are widowed are also two times more likely to use modern contraceptive methods compared to single women when all the other variables in the model are held constant.

Table 7.3:5 estimated odds ratios of using modern contraceptive methods conditional on functional limitation, presence of an impairment and socio-demographic characteristics

Variable	Model 1: Functional limitation status only		Model 2: Functional limitation status and Presence of an impairment		
	OR (95 % CI)	P-value	OR(95% CI)	P-value	Number
Functional limitation	1.10(0.99-1.23)	0.086	1.11(0.99-1.24)	0.063	
Age in years	1.02(1.01-1.04)	0.006	1.03(1.01-1.04)	0.005	
Wealth index	0.95(0.90-1.01)	0.076	0.95(0.89-1.01)	0.074	
Level of education					
No education (Ref)					
Less than Primary	1.55(1.10-2.17)	0.013	1.56(1.11-2.20)	0.012	
Primary Completed	1.49(0.98-2.25)	0.062	1.48(0.98-2.24)	0.063	
Secondary and above	1.56(0.74-3.30)	0.234	1.60(0.79-3.26)	0.187	
Place of residence					
Urban (Ref)					
Rural	1.19(0.82-1.73)	0.354	1.18(0.83-1.70)	0.352	
Marital Status					
Never Married (Ref)					
Married or Cohabiting	1.93(1.23-3.04)	0.005	1.90(1.23-2.95)	0.005	
Separated or divorced	1.60(0.80-3.20)	0.184	1.59(0.80-3.17)	0.180	
Widowed	2.37(1.06-5.26)	0.035	2.32(1.06-5.10)	0.037	
Impairment					
No impairment (Ref)					
Has an Impairment			0.74(0.22-2.45)	0.510	
Constant	0.06(0.03-0.14)	0.000	0.06(0.03-0.14)	0.000	
Number of Observations					2,365

[7]Source: MWHS-2003 and MDHS-2004

[7]

7.3.3.2 HIV counselling

Further to the examination of variation in use of modern contraceptive methods among women with functional limitations, the study also examined access to HIV counselling services among women who had given birth in the last two years before the survey, with functional limitations only, and with functional limitation and impairments. Table 7.3:6 presents the results obtained from regressing the utilization of HIV counselling methods with functional limitation only (model 1) and with functional limitation and impairment (model 2). The results in model 1 (with functional limitation only) in table 7.3:6 indicates that there is a significant association between experiencing functional limitations and accessing HIV counselling services. A unit increase in functional limitation reduces the odds of accessing HIV counselling services by 60%. The reduction in use of HIV counselling methods by functional limitations continues to be significant even after including the impairment variable in the model. Presence of an impairment on the other hand is not significantly associated with the utilization of HIV counselling services during antenatal visits.

With regards to socio-demographic variables, only age of the woman and level of education are significantly associated with access to HIV counselling services. A unit increase in age increases the odds of accessing HIV counselling services by 3%. This increase in access occurs even when an impairment variable is added in the model. Level of education also increases the utilization of HIV counselling services; women who have completed their primary education are three times more likely to access HIV counselling services compared to women with no education. Women with less than primary education are also 67% more likely to access HIV counselling services compared to women with no education when all the other variables in the model are held constant.

Table 7.3:6 estimated odds ratios of accessing HIV counselling services conditional on functional limitation, presence of an impairment and socio-demographic characteristics

Variable	Model 1: Functional limitation status only		Model 2: Functional limitation status and Presence of an impairment		
	OR (95 % CI)	P-value	OR(95% CI)	P-value	Number
Functional limitation	0.60(0.49-0.73)	0.000	0.59(0.49-0.72)	0.000	
Age in years	1.03(1.01-1.06)	0.010	1.03(1.01-1.06)	0.009	
Wealth index	1.00(0.90-1.13)	0.937	1.01(0.90-1.13)	0.895	
Level of education					
No education (Ref)					
Less than Primary	1.67(1.05-2.66)	0.031	1.67(1.05-2.68)	0.032	
Primary Completed	3.33(1.81-6.11)	0.000	3.37(1.80-6.28)	0.000	
Secondary and above	1.50(0.54-4.17)	0.425	1.53(0.54-4.36)	0.416	
Place of residence					
Urban (Ref)					
Rural	0.95(0.57-1.59)	0.844	0.95(0.57-1.59)	0.834	
Marital Status					
Never Married (Ref)					
Married or Cohabiting	1.99(0.77-5.13)	0.150	1.97(0.76-5.08)	0.157	
Separated or divorced	1.21(0.46-3.16)	0.689	1.17(0.45-3.05)	0.747	
Widowed	2.04(0.64-6.45)	0.220	2.03(0.64-6.43)	0.224	
Impairment					
No impairment (Ref)					
Has an Impairment			1.58(0.39-6.42)	0.512	
Constant	0.13(0.03-0.50)	0.004	0.13(0.03-0.51)	0.004	
Number of Observations					1,444

[8]Source: MWHS-2003 and MDHS-2004

7.3.3.3 Health facility delivery

In addition to contraceptive use and HIV counselling services, women's access to health facility delivery was also examined in this study. Delivery at the health facility was examined because literature on access to SRH services among persons with disabilities has demonstrated that women with disabilities fail to access reproductive health services because of poverty and environmental factors such as physically high maternity beds (Smith et al., 2004; Ahumuza et al., 2014; Mavuso and Maharaj, 2015). Therefore, table 7.3:7 presents the results obtained from regressing place of delivery with the functional limitation only (model 1) and functional limitation and impairment (model 2).

The results obtained in the model with functional limitation only indicates that there is no significant association between experiencing severe functional limitation and delivering at the health facility. This non-significant association between functional limitation and place of delivery continues even when we include an impairment variable in the model (model 2). Model 2 of table 7.3:7 further demonstrates that presence of an impairment is not significantly associated with delivering at the health facility.

With regards to the socio-demographic variables, the results in model 1 and 2 of table 7.3:7 indicates that levels of education, place of residence and marital status are significantly associated with delivering at the health facility. With regards to level of education, there is a statistical variation in place of delivery among women with no education and those with completed primary education. In the second model where an impairment variable has been included, women with completed primary education are more than two times more likely to deliver at the health facility compared to women with no education. In terms of place of residence, women living in rural areas have the lower odds of delivering at the health facility compared to women living in urban areas when all the other variables in the model are held constant.

Table 7.3:7 estimated odds ratios of health facility delivery conditional on functional limitation, presence of an impairment and socio-demographic characteristics

Variable	Model 1: Functional limitation status only		Model 2: Functional limitation status and Presence of an impairment		
	OR (95 % CI)	P-value	OR(95% CI)	P-value	Number
Functional limitation	0.95(0.81-1.11)	0.498	1.01(0.87-1.16)	0.926	
Age in years	1.01(0.98-1.05)	0.461	1.00(0.98-1.02)	0.987	
Wealth index	0.86(0.70-1.06)	0.145	0.72(0.63-0.81)	0.000	
Level of education					
No education (Ref)					
Less than Primary	1.27(0.91-1.79)	0.157	1.29(0.95-1.74)	0.098	
Primary Completed	4.11(2.07-8.15)	0.000	2.81(1.76-4.48)	0.000	
Place of residence					
Urban (Ref)					
Rural	0.40(0.25-0.66)	0.001	0.51(0.34-0.77)	0.000	
Marital Status					
Never Married (Ref)					
Married or Cohabiting	2.68(0.61-11.83)	0.187	1.15(0.47-2.84)	0.754	
Separated or divorced	3.28(0.93-11.56)	0.064	1.50(0.57-3.92)	0.413	
Widowed	7.23(1.14-45.76)	0.036	3.22(0.91-11.38)	0.070	
Impairment					
No impairment (Ref)					
Has an Impairment			0.66(0.32-1.35)	0.252	
Constant	1.11(0.19-6.39)	0.902	3.30(1.07-10.18)	0.038	
Number of Observations					1,444

[9]Source: MWHS-2003 and MDHS-2004

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[9]

7.3.4   Multinomial Logistic regression model

7.3.4.1   Professional health assistance during delivery

In addition to examining the variation in use of modern contraceptive methods, HIV counselling services and health facility delivery, this study also examined the variation in health professional assistance during delivery among women with functional limitations and those with and without impairments. Assistance during delivery was also examined in relation to measures of disability because the literature has shown that most health professionals do not have the skills or knowledge on how to manage the reproductive health needs of women with disabilities (Nosek *et al.*, 1995; Lee *et al.*, 2015). Therefore, table 7.3:8 presents the results obtained from the modelling of health professional assistance during child birth by functional limitation status only (model 1) and functional limitation status and presence of an impairment (model 2).

The results presented in model 1 of table 7.3:8 indicates that there is no statistical association between a woman's functional limitation status and being assisted by a traditional birth attendant relative to being assisted by a doctor, nurse or midwife during childbirth. The non-statistical association continue even when an impairment variable is added into the model.

With regards to the socio-demographic variables, the results in table 7.3:8 indicates that level of education is significantly associated with the relative risk ratio of being assisted by a traditional birth attendant relative to being assisted by a doctor, nurse or midwife. Women who have completed primary school have an increased relative risk ratio (RRR=0.20) of being assisted by a traditional birth attendant relative to being assisted by a doctor, nurse or midwife when all the variables in the model are held constant.

With regards to the relative risk ratio of being assisted by a relative or friend relative to being assisted by a doctor, nurse or midwife, the results in table 7.3.8 in both the model with functional limitation status only and the model with both functional limitation and impairment indicates that place of residence is significantly associated with the relative risk of being assisted with a relative or friend relative to being assisted with a doctor, nurse or midwife during child birth. Women who live in rural areas have an increased relative risk ratio (RRR=2.56) of being assisted by a relative or friend relative to being assisted by a doctor, nurse or midwife during child birth, when all the other variables in the model are held constant.

Table 7.3:8 Estimated Relative risk ratios of being assisted by a doctor, nurse or midwife conditional on functioning status, presence of an impairment and socio-demographic characteristics

Variable	Model 1: Functional limitation status only		Model 2: Functional limitation status and Presence of an impairment		
	RRR (95 % CI)	P-value	RRR(95% CI)	P-value	Number
Traditional Birth attendant					
Functional limitation	1.29(0.92-1.82)	0.139	1.29(0.92-1.81)	0.140	
Age in years	0.99(0.95-1.02)	0.415	0.99(0.95-1.02)	0.417	
Wealth index	0.93(0.79-1.10)	0.406	0.93(0.79-1.10)	0.406	
Level of education					
No education (Ref)					
Less than Primary	0.68(0.39-1.17)	0.159	0.68(0.39-1.17)	0.159	
Primary Completed	0.20(0.09-0.42)	<0.001	0.20(0.09-0.42)	<0.001	
Secondary and above	0.10(0.02-0.63)	0.015	0.10(0.02-0.63	0.015	
Place of residence					
Urban (Ref)					
Rural	1.68(0.76-3.74)	0.195	1.68(0.76-3.74)	0.195	
Impairment					
No impairment (Ref)					
Has an Impairment			1.08(0.29-3.98)	0.908	
Constant	0.78(0.22-2.81)	0.701	0.78(0.22-2.81)	0.698	
Relative or friend					
Functional limitation	1.16(0.93-1.43)	0.177	1.15(0.92-1.44)	0.215	
Age in years	0.99(0.95-1.02)	0.444	0.99(0.95-1.02)	0.458	
Wealth index	1.02(0.85-1.23)	0.839	1.02(0.85-1.23)	0.843	
Level of education					
No education (Ref)					
Less than Primary	0.51(0.32-0.81)	0.005	0.51(0.32-0.81)	0.005	
Primary Completed	0.23(0.11-0.50)	<0.001	0.23(0.11-0.50)	<0.001	
Secondary and above	0.05(0.00-0.57)	0.017	0.05(0.00-0.56)	0.016	
Place of residence					
Urban (Ref)					
Rural	2.56(1.19-5.48)	0.017	2.56(1.19-5.49)	0.017	
Impairment					
No impairment (Ref)					
Has an Impairment			1.26(0.36-4.37)	0.712	
Constant	0.29(0.07-1.27)	0.098	0.29(0.06-1.30)	0.102	
Number of Observations					1,444

To sum up, an examination of the socio-demographic characteristics of the sampled populations has shown that;

- A high proportion of women with impairment were aged between 35 and 49, and were mostly living in the rural areas and were either married or cohabiting.

- The descriptive results have also shown that 10.2% of the women reported to have experienced some moderate functional limitations, and 11.9% reported to have experienced some severe or extreme levels of functional limitations during the 30 days before the survey.

- Most of the women who reported having experienced severe or extreme limitations were aged between 18 and 24 and were from the highest wealth quintile.

With regards to the association between the measures of disability and the sexual and reproductive health service variables, the results in this chapter have shown that;

- Impairment measures of disability are non-significantly associated with use of modern contraceptive methods, utilization of HIV counselling services, place of delivery and professional health assistance during delivery.

- The test of association results have also shown that functional limitation measures of disability are non-statistically associated with use of modern contraceptive methods, place of delivery and professional health assistance during delivery , but are statistically associated with utilization of HIV counselling services.

Concerning the variation in use of sexual and reproductive health services among women with impairment and functional limitations who had given birth in the last two years before the survey, the results obtained from the logistic regression models have shown that:

- There is a no statistically significant relationship between the use of modern contraceptive methods and functional limitations at the 95% level of significance, even though a unit increase in functional limitation increases the odds of using modern contraceptive methods by 10%.

- The logistic models have further demonstrated that a unit increase in functional limitation reduces the odds of utilizing HIV counselling services by an odds ratio of 0.60.

- The results obtained in this chapter have also shown that there is no significant relationship between place of delivery and functional limitations.

- The logistic regression results in this chapter have further demonstrated that there is no statistically significant relationship between being assisted by a health professional assistance during childbirth and functional limitation.

7.4 Discussion of the results obtained from analysing the relationship between disability measures and uptake of SRH services

This study aimed to analyse the relationship between measures of disability and uptake of sexual and reproductive health services. This was achieved through the use of binary and multinomial logistic regression techniques. Before employing the logistic regression techniques, cross-tabulations and tests of associations between impairment and functional measures of disability and sexual and reproductive health services variables were conducted. The results in table 7.3:1 indicate that 3.8% of the women were impaired whilst table 7.3:2 indicates that 10.2% of the women reported to have experienced at least one moderate limitations and 11.9% of the women reported to have experienced at least one severe or extreme functional limitation. The impairment results correspond to the 2008 Malawi Population and Housing Census report which estimated the total population of women aged 15 and above, with disabilities to be 3.8% (NSO, 2010a). The functional limitation results on the other hand, supports the WHO disability estimate of 10% (WHO and World Bank Group, 2011). The similarity between these study findings and those of the population and housing census and the WHO estimates indicates that the results obtained in this study are reliable.

The difference in the proportion of impaired and those with functional limitations, demonstrates the variation in the approaches used to measure disability. As discussed in section 2.3 on the measurement of disability in the literature chapter, impairment measures of disability mainly focus on severe disabilities (Palmer and Harley, 2012) whilst functional measures, measure those with moderate and severe disabilities (Mont, 2007a). Using impairment measures alone to collect disability data may not be sufficient for sexual and reproductive health policy formulation because the results in table 7.3:1 have shown that 10.7% of women with no impairments reported to have experienced severe or extreme levels of functional limitation. Therefore, to accurately estimate the proportion of persons with disabilities who may need access to sexual and reproductive health services, there is a need for using both impairment and functional limitation measures of disability during population censuses and surveys.

Apart from the proportional distribution of persons with impairment and functional limitations, the descriptive results in this chapter have also illustrated that a high proportion of women with impairment are aged between 35 and 49. The findings on the age distribution of women with

impairment corresponds to the findings by the World health Organization (WHO) in the 2011 world report on disability. The WHO reported that a majority of persons with disabilities are aged 49 and above. According to WHO, the higher disability rates among older women is a reflection of an accumulation of health risks across an individual's lifespan. The health risks includes diseases, injuries and chronic illness such as HIV and AIDS (World Health Organization, 2011). Even though the WHO has suggested that disabilities in older women are a reflection of an accumulation of health risks, it is difficult to explain why women in the age group 18 to 24 in this study reported higher levels of severe or functional limitations compared to the older women. Thus, there is a need for investigating why women in the younger reproductive ages (18-24) are reporting higher levels of functional disabilities compared to the older women.

 With regards to marital status, the descriptive statistics in table 7.3.1 have demonstrated that a high proportion of women with impairments and functional limitations are married (54.8% and 65.8% respectively). However, even though a high proportion of the impaired or functionally limited women are married or cohabiting, their divorce or separation rates are higher compared to those of women without impairments or functional limitations (25.7% versus 11.4%). The finding on higher divorce rates correspond to findings that have been observed in Zambia, Ghana, Uganda and South Africa (Smith *et al.*, 2004; Wazakili, Mpofu and Devlieger, 2006; Ahumuza *et al.*, 2014; Mavuso and Maharaj, 2015). For example, in South Africa, women with disabilities reported that men in the Durban area pretend to love women with disabilities , but after sometime they abandon them for women with no disabilities (Mavuso and Maharaj, 2015). In the case of Malawi, women with disabilities get divorced or separated because of their inability to participate in farming activities, the main economic activity in the country (Munthali, Mvula and Ali, 2004). The difference in the explanation for higher divorce rates among women with disabilities in the region indicates that there is no single explanation of why women with disabilities experiences divorces in the region.

When analysing the relationship between impairment and utilization of sexual and reproductive health services using logistic regression models, the study anticipated that the impairment variable would influence uptake of SRH services. The study-anticipated impairment to influence utilization of the SRH services because a number of studies on access to SRH services in developed countries have indicated that impairments contributes to the challenges faced by women with disabilities when accessing sexual and reproductive health services (Nosek *et al.*, 1995; Welner, 1996; Becker, Stuifbergen and Tinkle, 1997). For example, Rieve (1989) cited in Becker et al (1997) found women with decreased pelvic sensation to experience difficulties in

using intrauterine devices (IUD) because of their reduced ability to perceive discomfort or pain. The results in the logistic regression models of this study, on the other hand, have demonstrated that the presence of an impairment does not influence the uptake of sexual and reproductive health services. The lack of influence by the impairment variable in this study could be due to the number of women with impairments or the design of the study, which in this case was a cross-sectional study. In this study, only 80 women were observed to have impairments out of the 2365-sampled population. The smaller sample therefore, necessitates the need for conducting a sexual and reproductive health focused disability study where women with various impairment will be oversampled and studies for a longer period such as three years.

The logistic regression results obtained in this study have indicated that impairment measures of disability are not significantly associated with the uptake of modern contraceptive methods or HIV counselling services. An explanation for the lack of association between impairment and use of modern contraceptive methods and HIV counselling services could be related to the primary health care delivery system of the country. In an attempt to scale up the primary health care delivery system in rural settings, the Malawi government introduced a programme of Health Surveillance Assistants (HSAs) in the 1960s (Kauye *et al.*, 2011). HSAs were introduced as temporary community-based health workers who assisted with the delivery of health services such as smallpox vaccinations. By 1995, the position of HSAs was made permanent and the role of the HSAs was also increased to include delivery of Health programmes including Family planning, HIV care and the treatment of TB (Kauye *et al.*, 2011; Prata *et al.*, 2011). The availability of the HSAs in the communities and the increase in their responsibilities has meant that people no longer need to go to the health facilities to access contraceptive methods such as injectables and HIV counselling services. This means that people with impairments no longer face issues of accessibility because the HAS can come to their house or their communities and deliver the services. In addition to the availability of HSAs, in Malawi, there is policy where each pregnant woman is HIV tested to reduce the prevalence of mother to child transmission (Bicego, Boerma and Ronsmans, 2002). Thus, whether you are impaired or not you are tested to address the objective of this safe motherhood programme. The presence of the HSAs in the rural communities and the routine testing of the HIV virus during antenatal visits explains why the impairment variable had no statistical significance on the utilization of modern contraceptive methods and HIV counselling services.

Apart from analysing the link between having an impairment and accessing SRH services, the study also analysed the relationship between experiencing functional limitation and utilization of the SRH services. The results from both multiple logistic regression and multinomial logistic regression above indicates that functional limitation is not significantly associated with a

woman's uptake of modern contraceptive methods, place of delivery or the use of professional health assistance during delivery. The lack of a significant association between functional limitations and use of modern contraceptives, in the country may be related to the presence of HSAs in the rural communities, as explained in relation to the women with impairments.

Concerning the likelihood of being assisted by a health professional during childbirth, the study has found that among women with impairments a unit increase in functional limitation increases the risk of being assisted by a traditional birth attendant relative to a doctor, nurse or midwife. These study findings do not relate to what other researchers have found on the relative risk of being assisted by a health professional when a woman experiences functional difficulties (Chakraborty *et al.*, 2003; Redshaw *et al.*, 2013). For example, in rural Bangladesh, a multivariate analysis on utilization of maternal health care among women with severe health conditions found women with severe health condition or functional limitations to be twice as likely to seek care from a doctor or nurse compared to women with no severe conditions (Chakraborty *et al.*, 2003). The difference in the study findings between this study and the one in rural Bangladesh could be related to the distance to the nearest health facilities. The Bangladesh study indicates that the distance to the nearest health facility is a walkable distance of less than 1 km whilst in Malawi the average distance to the nearest health facility is 5 km (Chakraborty *et al.*, 2003; NSO, 2016a). For most impaired women with functional limitations, it means that they have to hire a bicycle, an oxcart or a taxi to get to the nearest health facility. The use of transport services in most cases is expensive; as a result women with severe functional limitations end up being assisted by a traditional birth attendant (Kumbani *et al.*, 2013; NSO, 2016a).

In analysing the relationship between disability measures and the uptake of sexual and reproductive health services, the study used the age of the participant, household income, and level of education, marital status and place of residence as control variables. In terms of education, this study has found that a woman's level of education increases her odds of utilizing modern contraceptive methods HIV counselling services and delivering at a health facility but decreases the likelihood of being assisted by a traditional birth attendant, or relative or friend, relative to being assisted by a doctor, nurse or midwife. These findings contrast with findings in Kwazulu-Natal, a province in South Africa by Mavuso et al (2013). Mavuso et al (2013) found that among persons with disabilities who included those with visual and physical disabilities, better education had no association with knowledge and use of sexual and reproductive health services. The current study findings support the United Nations Population Fund (UNFPA) assertion that education gives women with disabilities an opportunity to develop their human capital skills,

which makes it possible for them to seek sexual and reproductive health care services (Arcella *et al.*, 2009). Even though the overall education status of the impaired and functionally limited women contributes to their utilization of SRH services, the findings from this study have indicated that women in Malawi do not need to finish their primary education for education to influence their health-seeking behaviour. For example women, women with less than primary education have significantly higher odds of using modern contraceptive methods (odds ratio = 1.560) compared to women with no education.

With regards to place of residence, the study has shown that women living in rural areas have the lower odds of giving birth at the health facility compared to home and an increased relative risk ratio of being assisted by a relative or friend relative to being assisted by a doctor or nurse or midwife. These study findings correspond to findings in rural Nepal by Morrison et al (2014). Morrison et al (2014) found 22 of the 27 rural women that they had interviewed preferred giving birth at home compared to a health facility. The women preferred to give birth at home compared to the health facilities because they were embarrassed to expose their bodies to the health service providers and because the health facility infrastructures, such as maternity beds, were not conducive to the reproductive needs of these women (Morrison *et al.*, 2014). Concerning Malawi, Munthali et al (2004) found rural women who had given birth at home to have done so because the labour had been premature and because of transportation costs. The similarity in the current study's findings to those of rural Nepal demonstrates the need for sensitizing women on the health benefits for giving birth at the health facility.

7.5   Conclusion

In conclusion, this study aimed to examine the relationship between measures of disability and uptake of sexual and reproductive health services. The study has found that when disability is measured as an impairment the proportion of persons with disabilities is small, whilst when disability is measured as a functional limitation the proportion of persons with disabilities is high. The study has also found that impairment measures of disability are not statistically significantly associated with any of the four sexual and reproductive health services but functional limitation measures are significantly associated with HIV counselling services. The results obtained from this chapter leads to the conclusion that impairment and functional measures of disability are not associated with the utilization of sexual and reproductive health services in Malawi. However, the design and sampling of the study could have contributed to the results obtained from the logistic regression outputs. For example, the sample size of women with impairment, which in this case was 80, could have contributed to the lack of influence of the impairment variable on the utilization of sexual and reproductive health services. The aggregate measurement of functional

disability could also have affected the relationships between the functional disability and utilizations of sexual and reproductive health services. Apart from the disability measures, the sexual and reproductive health variables used could also have contributed to the non-significant outcomes.

To accurately conclude that impairment and functional measures of disability are not associated with the utilization of sexual and reproductive health services, this study suggests that a survey should be conducted where women with various types of impairments are randomly oversampled. The impairment types would need to include both physical and intellectual impairments. When analysing the data, the sexual and reproductive health behaviour of women with physical impairments could be compared with that of women with intellectual impairments. The two main groups of impairment could also be separately compared with women with no impairments.

 Regarding functional disabilities, this study suggests that instead of analysing functional disability as an aggregate variable, the various health domains (mobility, affect, vision, personal relationships, sleep and energy, pain and discomfort, cognition and self-care) need to be analysed separately. The current study did not directly link a specific domain with a sexual and reproductive health variable because the focus was on the measurement of disability. With regards to the sexual and reproductive health variables, the study proposes an examination of the disability measures with other sexual and reproductive health measures such as, number of antenatal visits during pregnancy, or number of postnatal visits and HIV testing or access to Antiretroviral treatment.

When analysing use of sexual and reproductive health services among persons with disabilities in this study, the study focused only on women because the 2003 Malawi World Health survey only corrected sexual and reproductive health information from women. The implication is that it is difficult to generalise about the sexual and reproductive health behaviour of persons with disabilities in the country. Even though men and women with disabilities may experience some similar health access challenges, there are other sexual and reproductive health access challenges that are uniquely experienced by men. For example, even though both men and women with disabilities may experience challenges in accessing sexual and reproductive health information due to limited availability of alternative formats such as braille; men may be deprived of basic information such as accessible abuse reporting centres because of the misconception that men with disabilities do not experience sexual and physical abuse (WHO and UNFPA, 2009).

The other limitation of the results obtained in this chapter is that information on HIV counselling services, place of delivery and professional health assistance during child birth was collected from women who had given birth two years before the survey. The collection of information from only women who had given birth two years prior to the survey is limiting because research has indicated that as the level of functional disabilities increases the probability of giving birth decreases among women with disabilities (Iezzoni *et al.*, 2014; Murthy, John and Sagar, 2014). For example in a study of women with chronic physical disabilities in the United States of America, Iezzoni et al (2014) found   women with severe functional limitations to have a significant lower odds of pregnancy compared to women without functional limitations. The reduction in the odds of pregnancy among women with severe functional disabilities implies that a high proportion of women with severe functional limitations could not have given birth two years prior to the survey. Therefore, by only collecting information from those women who had given birth within the last two years before the survey meant that a high proportion of women with severe functional limitations or disabilities were excluded from the sample. Thus the results obtained from this chapter may not provide a complete picture of the sexual and reproductive health access behaviour of women with disabilities in the country. This study, therefore recommends a further research on access to sexual and reproductive health services where the sexual and reproductive health information such as HIV counselling will be collected from women who had given birth five years prior to the survey.

8 Chapter 8: Investigating the inclusion of persons with disabilities sexual and reproductive health needs in Malawi's health policies and programmes

8.1 Introduction

An examination of the link between impairment and functional measures of disability and uptake of sexual and reproductive health services (SRH) in this study has shown that there is no significant variation in use of sexual and reproductive health services between women with disabilities and those without disabilities. Despite these observations, literature on the sexual and reproductive health of persons with disabilities in Malawi indicates that persons with disabilities continue to face challenges when accessing sexual and reproductive health services compared to persons without disabilities (Loeb and Eide, 2004; Munthali, Mvula and Ali, 2004; Mji et al 2008; Munthali *et al.*, 2017). For example, Munthali et al (2017) found that persons with disabilities were experiencing challenges such as the cost of accessing health care and the poor attitude of health services providers. The continued challenges faced by persons with disabilities despite there being no variation in access of the services necessitates the need to examine Malawi's sexual and reproductive health policies and programmes. This chapter therefore discusses the inclusion of persons with disabilities sexual and reproductive health needs in the country's policies and programmes.

The examination of sexual and reproductive health policies and programmes is also premised on the available evidence that indicates that the sexual and reproductive health needs of persons with disabilities are rarely incorporated in sexual and reproductive health policies and programmes (WHO and UNFPA, 2009; Kwadwo, Anafi and Sekyere, 2014; Ivanova, Dræbel and Tellier, 2015). For example, a review of sexual and reproductive health policies in Ukraine, Spain, Scotland and the Republic of Moldova by Ivanova et al (2015), has indicated that only Spain's SRH policy has a detailed description of the needs of persons with disabilities (Ivanova, Dræbel and Tellier, 2015) . A review of sexual and reproductive health policies in Ghana, also indicates that the sexual and reproductive health needs of persons with disabilities are either cursorily mentioned or negatively described (Kwadwo, Anafi and Sekyere, 2014). This omission and negative portrayal of the sexual and reproductive health needs of persons with disabilities affects the provision of SRH services to persons with disabilities to the extent that only a small proportion of person with disabilities are able to access the health services. For example, in Uganda, only

37% of women with disabilities deliver at a health facility compared to 50% of women without disabilities (Bwalya *et al.*, 2017).

It is from this basis that this study aims to explore whether or not the sexual and reproductive health needs of persons with disabilities are included in Malawi's health policies and programmes. To address this study objective, nine sexual and reproductive health policies and strategies were evaluated. Ten key informant interviews with policy makers and programme developers working on sexual and reproductive health and disability in Malawi were also conducted to gain a deeper understanding of how sexual and reproductive health needs of persons with disabilities are addressed in Malawi's health policies and programmes. This chapter therefore, discusses the results obtained from the evaluation of the policy documents and the key informant interviews.

8.1.1 Background to the Sexual and Reproductive Health policies of Malawi

Sexual and reproductive health services have been offered in Malawi ever since the 1960's. During this period, each sexual and reproductive health programme, such as family planning or maternal and child health, had its own guiding principles or policies (Ministry of Health and Population, 2002). This vertical approach to service delivery made it hard for the Ministry of Health, particularly the Department of Reproductive Health, to coordinate their service provision. This difficulty in co-ordination led the Ministry of Health, with its implementing partners including the United States Agency for International Development (USAID), to develop a Sexual and Reproductive Health policy to assist in the coordination of the sexual and reproductive health services. The decision to develop this sexual and reproductive health policy also came about due to the adoption of the 1994 International Conference on Population and Development (ICPD) Programme of action (PoA). The ICPD PoA emphasised the need to integrate sexual and reproductive health services and to discontinue the use of the vertical approach to reproductive health service delivery (Ministry of Health and Population, 2002).

Following the adoption of the 1994 ICPD Programme of Action in 1997 and acceptance of the need to improve coordination of reproductive health services, the first Sexual and Reproductive Health Policy in Malawi emerged. This policy was developed in April 2001 but published in 2002 and was called the *Reproductive Health policy*. The *2002 Reproductive Health policy* was developed not only to guide in the implementation of the Reproductive health programmes but also to help manage the reproductive health conditions of the country d at a time (Ministry of Health and Population, 2002). At the time at which the *Reproductive Health policy* was produced, the reproductive health situation of Malawi was judged to be among the poorest in the sub-

Saharan African region. The average number of children per woman (completed fertility) was 6.3 births whilst the average for the region was at 5.5 children (Tabutin, Schoumaker and Rabenoro, 2004). The Childhood mortality was high with under-five mortality at 189 per 1000 live births and infant mortality at 104 per 1000 live births (Malawi National statistics office, 2001).

The *2002 Reproductive Health Policy* was later revised to incorporate the sexual and reproductive health issues that had emerged during the implementation period (2002-2008) and the newly enacted 2006 African Union Maputo Plan of Action (Ministry of Health, 2009). During the implementation of the 2002 Reproductive Health policy, a range of sexual and reproductive health issues emerged due to national and International commitments and the development of the Malawi Growth and Development Strategy. The emerging issues included Basic Emergency Obstetric and Neonatal Care (BEmONC); Community Based Maternal and Neonatal Care; Cervical Cancer Screening; Youth Friendly Health services; Anti-Retroviral Therapy and Prevention of Mother to Child Transmission (PMTCT) (Ministry of Health, 2009). With regards to the 2006 African Union Maputo Plan of Action, these Plans of Action had recommended to its member states that they integrate the prevention and management of STI, HIV and AIDS with Malaria service provision within Primary Health Care. The Maputo Plan of Action also recommended its member states to reposition Family planning as a key development strategy and position adolescent sexual and reproductive health as a strategy for empowerment, development and social wellbeing (African Union, 2006). With these recommendations, the Ministry of Health through the department of reproductive health revised the *Reproductive health policy* and renamed it the *National Sexual and Reproductive Health and Rights (SRHR) policy*.

The revised *National Sexual and Reproductive Health and Rights* policy aimed at addressing the sexual and reproductive health problems that had risen in various age groups (Ministry of Health, 2009). It was also developed to provide a framework for implementing sexual and reproductive health programmes in the country. It focused on improving the accessibility of family planning services ; on reducing maternal and infant mortality rates; reducing sexually transmitted infections and HIV and AIDS; reducing reproductive cancers, reducing infertility rates, improving the sexual and reproductive health of young people; reducing incidences of Obstetric fistula and increasing the involvement of men in sexual and reproductive health programmes (Ministry of Health, 2009).

Even though the policy was aimed at addressing the emerging health issues, there were some difficulties in the implementation of the policy. Men were reluctant to participate in the SRH programmes because they felt that they were being ignored by the health service providers, due to the fact that they were not allowed to enter the examination room during pre-natal care

services (Kululanga, Sundby and Chirwa, 2012). The implementation of the SRHR policy also affected the collection of maternal and child health data from traditional birth attendants (TBAs), because the TBAs stopped recording the births that were occurring in rural communities, because the policy had requested them not to provide delivery services (Kanjo, 2011).

To address the challenges encountered during the implementation of the *2009 National Sexual and Reproductive Health and Rights (SRHR) policy*, to incorporate emerging issues such as the adoption of the Sustainable Development Goals (SDGs) and to revise the targets that had been set in the 2009 SRHR policy, the SRHR policy was revised in 2016 (Ministry of Health, 2017). This revision of the policy was in line with both national and international recommendations on SRHR service provision. At a national level the policy was developed in line with Malawi Government Development Strategy (MGDS), the Malawi National Sexual and Reproductive Health and Rights strategy, the Roadmap for Accelerating the Reduction of Maternal and Neonatal Mortality and Morbidity and the Malawi Gender policy (Ministry of Health, 2017). At an international level, the SRHR policy was developed in line with the 1994 ICPD Programme of Action, the African Union Maputo Plan of Action and the Sustainable Development Goals (SDGs).

The 2016 revised SRHR policy , aims " to provide a framework for provision of accessible, acceptable and affordable, comprehensive sexual and reproductive health and rights services to all women, men and young people of Malawi through informed choice, to enable them attain their reproductive rights and goals safely", (Ministry of Health, 2017). The current SRHR policy was also developed based on the country's reproductive health estimates. The 2015-16 Malawi Demographic and Health Survey had reported that the period total fertility rate was at 4.4 children down from the 5.7 of the 2010 MDHS (NSO, 2011;2016b). The maternal mortality ratio was also estimated to be at 439 per 100,000 live births. Infant mortality was at 42 deaths per 1000 live births. Teenage pregnancy was on the rise, it was estimated at 29% up from 26% in the 2010 MDHS (NSO, 2011;2016b). All these reproductive health estimates necessitated the need to revise the SRHR policy and implement SRHR programmes.

8.2   Data used to investigate the inclusion of persons with disabilities SRH needs in Malawi's health policies and programmes

To assess the extent to which the sexual and reproductive health needs of persons with disabilities have been included in Malawi's sexual and reproductive health policies and programmes, this study evaluated nine health policy documents that are available in the country.

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The study also conducted key-informant interviews with policy-makers, and programme developers working on disability and sexual and reproductive health service programmes. A health policy in this study refers to "formal, written documents, rules, and guidelines that present policy makers' decisions about what actions are deemed legitimate and necessary to strengthen the health system and improve health", (Ivanova, Dræbel and Tellier, 2015). Policies in this case not only relate to the actual policy documents, but also strategies and action plans or programmes.

8.2.1   Policy documents

Health policies that have been evaluated in this study were collected from Malawi's Ministry of Health website, United Nations Population Fund (UNFPA) Malawi website, Google, Google Scholar and PubMed. From these websites and search engines nine policy documents (six health and two disability policy documents) were collected. The nine policy documents are, the 2017-22 Malawi's *National Sexual and Reproductive Health and Rights (SRHR)* policy, the 2015-2020 Malawi *National Youth Friendly Health services Strategy*, the 2017-2022 *Malawi Health Sector Strategic Plan II*, *Malawi's National Health Policy*, the *2011-2016 Malawi National HIV and AIDS policy*, and the *2016-2020 Malawi National Cervical Cancer Control Strategy* the *2006 Malawi policy on Equalization of Opportunities for Persons with Disabilities* and the Malawi's National Disability Policy.

Box 8.2:1 Policies that guide in the provision of sexual and reproductive health services in Malawi

No.	Name of the policy	Year of publication	Abbreviation
1	National Health Policy	2018	NHP
2	Malawi National sexual and Reproductive health and Rights Strategy 2011-2016	2012	NSRHRS
3	Health Sector Strategic Plan II 2017-2022	2017	HSSP II
4	National Sexual and Reproductive Health and Rights (SRHR) policy 2017-2022	2017	SRHR
5	National Cervical Cancer Control Strategy 2016-2022	2017	CECAS
6	National Youth Friendly Health Services Strategy 2015-2020	2015	NYFHSS
7	National HIV and AIDS Policy 2011-2016	2011	NHAP
8	National Disability policy draft	not published	
9	National Policy on Equalization of opportunities for persons with disabilities	2006	NPEOPD

8.2.2   Key informant interviews

Key informant interviews were conducted in Malawi from the 25th of September (2017) to the 15th of December 2017, following the ethical approval of the University of Southampton Ethics and Research Governance Committee. Locally, permission to conduct the study was sought and obtained from the District Commissioners (DC) of Zomba, Blantyre and Lilongwe. These districts are the districts where various government offices, civil societies and non-governmental organization of interest are found. The target population for key informant interviews were policymakers or policy formulators and programme developers in the Ministry of Gender, Children, Disability and Social welfare, Ministry of Health, Banja La Mtsogolo (BLM), Family

Planning Association of Malawi (FPAM), Malawi Human Rights Commission, Malawi Council for the Handicapped (MACOHA), Disabled Women in Development (DEWODE) and Christian Blind Mission (CBM). These government ministries, civil society organization and non-governmental organizations were targeted because they are the key players in the development and implementation of disability and sexual and reproductive health policies and programmes.

Participants in the key informant interviews were identified with the assistance of social researchers working on disability and sexual and reproductive health at Chancellor College a constituent college of the University of Malawi. When potential participants had been identified, they were contacted by email or telephone. When they accept the invitation to participate in the study, they were emailed a participant information sheet (attached in Appendix 1) to inform them of the study objectives and the sort of information that they would be expected to provide. Participants were also asked to choose a day when they would be available to be interviewed. On the day of the interview, participants were asked to sign a consent form (attached in Appendix 1) and were informed that the interview would be recorded. Overall, ten key informant interviews were conducted from the sampled organizations.

During the interview, a study guide was used to facilitate the understanding of the inclusion of sexual and reproductive health needs of persons with disabilities in Malawi's disability and sexual and reproductive health policies and programmes. Four different study guides were used in this study because the key informants were from different health and disability sectors. The first guide had questions relating to the development of disability policies, the second one related to the development of sexual and reproductive health policies, the third one related to the implementation of disability programmes, and the fourth one related to the implementation of sexual and reproductive health programmes. Box 8.2:2 provides a summary of the questions that guided the key informant interviews.

Box 8.2:2 Guide for key informant interviews

1. What was the process that led to the identification of the issues in this policy?

   Probe: what was the goal? What data was used and why?

2. How did you prioritise beneficiaries of this policy? Or who does this policy serve?

   Probe: Did this prioritization process consider special groups of people or vulnerable population groups such as people with disabilities? How is this reflected in the policy?

3. How do you understand disability?

   Probe: How is this understanding evidenced in the policy?

4. What issues about people with disabilities does the policy address?

   Probe: How did you identify these issues? What understanding of disability did you use?

5. How do you think the understanding of disability addresses issues or concerns of people with disabilities in this policy with respect to their sexual and reproductive health?

6. What sexual and reproductive health services/activities do you implement concerning people with disabilities?

   Probe: How were these activities identified and designed? What guided the inclusion of the activities in the programme?

7. Do you think that the health services you provide adequately address the sexual and reproductive health needs of people with disabilities?

   Probe: for example, people without sight? In wheelchairs? With mental health problems?

8. Do you think there are any things missing in your provision of sexual and reproductive health services with reference to people with disabilities?

   Probe: why? What could be done to address these?

8.3   Methods used to investigate the inclusion of the sexual and reproductive health needs of persons with disabilities in Malawi

8.3.1   Policy documents

The nine policy documents in this study were analysed using the Equiframe framework, this is an analytical framework that was developed by Mann et al in 2011. The framework was developed to assists policy analysts in the evaluation of the extent to which health policies in low-income countries, particularly sub-Saharan African countries, address the 21 core concepts of human rights and the needs of 12 vulnerable groups through the ethos of universal, equitable and accessible health services (Mannan *et al.*, 2011; Ivanova, Dræbel and Tellier, 2015). The core concept of human rights in the Equiframe framework include non-discrimination, individualised service, participation, protection from harm, autonomy and integration (Mannan *et al.*, 2011). The vulnerable population groups are people with limited resources, women-headed households, children with special needs, displaced populations and persons with disabilities. According to Mann et al (2011), the core concepts of the Equiframe framework enable researchers to examine the objectives of the policy, what the policy intends to accomplish and how the policy objectives will be addressed.

The Equiframe framework has been used in this study because it focuses on the health needs of vulnerable population groups like persons with disabilities and can be modified to conform to the objectives of the study (Ivanova, Dræbel and Tellier, 2015). Other scholars, including Ivanova et al (2015) have also modified the Equiframe framework to suit the objectives of their study. For example, during the evaluation of the sexual and reproductive health policies of Spain, Scotland, Republic of Moldova and Ukraine, Ivanova et al (2015) modified the framework by reducing the 21 core human rights concepts to 11, and by adding six new vulnerable groups.

 The Equiframe framework has proven to be a useful framework for analysing health policies because it provides a benchmark for policy analysis and provides a means for policy revision and development (Mannan *et al.*, 2011; MacLachlan *et al.*, 2012). For example, using the Equiframe framework to analyse 51 policies from Malawi, Sudan, South Africa and Namibia, MacLachlan et al (2012) observed that there were inequities in most of the health policies that were sampled from the four countries. Despite being a useful analytical framework, the Equiframe Framework, as any framework, has been found to have some limitations. It does not provide guidelines on how to conduct the policy analysis, it just provides a list of human rights issues that a researcher can look for in the policy document (Amin *et al.*, 2011). The Equiframe was also mainly developed for low-income countries, particularly African countries, as such its description of vulnerable groups may

not apply to groups in other populations, for example in developed countries (Mannan *et al.*, 2011; Ivanova, Dræbel and Tellier, 2015). Researchers in other developing countries need to modify the description of the vulnerable groups to be able to use the framework. This lack of a universal description of vulnerable groups creates difficulties when comparing health policies across middle and low-income countries.

Using the Equiframe framework, the nine health policy documents were analysed by checking whether or not they have addressed the following core concepts of disability:

1. Disability: Has the policy mentioned persons with disabilities as one of their target populations? Has it included persons with physical, sensory, intellectual or mental health conditions?

2. Access: Does the policy support persons with disabilities' physical, economic and information access to sexual and reproductive health services?

3. Non-discrimination: Does the policy support the rights of persons with disabilities to have equal opportunity in receiving health care?

4. Individualised services: Does the policy support the rights of persons with disabilities to have individually tailored services to meet their needs and choices?

5. Integration: Does the policy promote the use of mainstream services by persons with disabilities?

6. Autonomy: Does the policy support the right of person with disabilities to consent, refuse to consent, withdraw consent, or otherwise control or exercise choice or control over what happens to him or her?   (Mannan *et al.*, 2011)

The quality of each policy document was then rated based on its commitment to address the above core concepts. Each core concept received a score in the range from 1 to 3 where;

1= Concept only mentioned

2=concept mentioned and explained

3=Specific policy actions identified to address the concept

8.3.2   Key informant interviews

Information collected from key informant interviews was analysed in Nvivo 11.4 using thematic analysis. Nvivo is a software programme that was developed by QSR international, and is used to manage and analyse qualitative data such as interviews and focus group discussions (Edhlund and

McDougall, 2017). A thematic analysis is a "a method for identifying, analysing, organizing describing and reporting themes found within a data set", (Nowell *et al.*, 2017). According to Braun et al (2006), thematic analysis is a useful technique for social researchers because it summarizes key features of the collected data and produces qualitative analyses that are suitable for informing policy development. Just like any other analytical technique, the thematic analysis technique has its own limitations. The main limitation relates to its flexibility, which enables researchers to have a range of analytical options because it does not require detailed theoretical and technological knowledge of other qualitative approaches such as grounded theory (Braun and Clarke, 2006; Nowell *et al.*, 2017). This flexibility "can lead to inconsistency and a lack of coherence when developing themes derived from the research data", (Nowell *et al.*, 2017).

The thematic analysis approach for the analysis of qualitative data requires the researcher to be familiar with the data and to note down the initial ideas found in the data (Braun and Clarke, 2006; Nowell *et al.*, 2017). The initial ideas are then developed into codes, which guide in the systematic analysis of the data. When analysing the data using the codes the researcher collates the data that is relevant to each code. The collated data in each code is then reviewed to identify potential themes. The researcher continues to review the themes to ensure that they are related to the information gathered from the qualitative research for the writing of a final report (Braun and Clarke, 2006).

 Information collected from the key informants was analysed using the thematic analysis technique. The researcher read the transcribed information to familiarise herself with the collected data. A review of the transcribed data indicated that there was use of international documents and a non-use of disability data, when developing sexual and reproductive health policies and programmes. The repeated inference of the interview accounts also revealed that the conceptual understanding of disability influenced the delivery of sexual and reproductive health services to persons with disabilities. Based on these observations the researcher decided to code the key informant data into three thematic areas. The thematic areas were the conceptual understanding of disability, factors that guide in the development of policies or programmes and the provision of sexual and reproductive health services to persons with disabilities. These proposed themes were discussed with a peer reviewer and it was agreed that the codes were a true reflection of the information collected during the key informant interviews.

8.4   Results of the policy analysis

This section begins with an overview of each health policy and its commitment to the six core concepts of the Equip frame framework that has been discussed in section 8.3.1. The remainder of the sections present the results from the key informant interviews.

8.4.1   Inclusion of the sexual and reproductive health needs of persons with disabilities in the SRHR policies and Strategies

An examination of the inclusion of the sexual and reproductive health needs of persons with disabilities in the nine policies, demonstrates that few policies have addressed the needs of persons with disabilities. Two policies mention persons with disabilities but do not provide a detailed description on how they will address the SRH needs of persons with disabilities. Two health policies have included persons with disabilities and provided the specific strategies that will be used to address the needs of persons with disabilities.

8.4.1.1   No attention given to persons with disabilities

Of the seven policy documents that relate to the provision of health services, three policy documents; the *National Health policy,* the *National Sexual and Reproductive Health and Rights strategy 2011-2016* and the *National Health Sector Strategic Plan II* do not target persons with disabilities or their sexual and reproductive health needs. There were efforts to address the needs of vulnerable population groups but the strategies do no specifically target persons with disabilities. For example, the National Health policy, targets vulnerable populations in its delivery of Universal Health Coverage of Essential Health Care services, but none of its strategies provides a description of persons with disabilities nor does it give details of how the sexual and reproductive health needs of persons with disabilities will be addressed.

In addition to the *National Health policy*, neither does the SRHR strategy 2011-2016 mention nor provide a detailed description of the sexual and reproductive health needs of persons with disabilities. The SRHR strategy was developed, "to promote through informed choice, safer reproductive health practices by men, women and young people, including the use of high quality, accessible reproductive health services", (Malawi Government, 2012). The strategy aims to achieve the promotion of safer reproductive health practices through (1)family planning; (2)maternal and neonatal health (including management of unsafe abortion); (3)prevention and management of STI or HIV and AIDS; (4) prevention, early detection and management of cervical ,

breast and prostate cancer, infertility; (5) mitigation of harmful practices and (6)obstetric fistula. Even though the strategy targets adolescents or young people, commercial sex workers and persons in prisons, in addressing all of these components, none of these components has a specific strategy or activity that targets persons with disabilities. Yet persons with disabilities are at an increased risk of acquiring STI or HIV and AIDS, due to the cultural belief that it is possible to be cured of HIV by having sexual intercourse with a person with disability (Munthali, Mvula and Ali, 2004).

The *Health Sector Strategic Plan II* (HSSP II) also does not specifically target persons with disabilities in its strategies. This policy document purposes to "move towards a Universal Health Coverage (UHC) of quality, equitable and affordable Healthcare with the aim of improving health status, financial risk protection and client satisfaction", (Malawi Government, 2017). The strategy defines Universal Health Coverage as "a situation where everyone - irrespective of their ability to pay - gets the health services they need in a timely fashion without suffering any undue financial hardships because of receiving care" (Malawi Government, 2017). To achieve this Universal Coverage, the HSSP II, outlines eight strategies, one of which it to increase equitable access to and improve quality health care services. Even though this strategy prioritises the increase of equitable access to quality health care, it does not provide a detailed description of the target populations such as women, young people or persons with disabilities. Thus, it assumes that by improving the health care systems all the sub-population groups including persons with disabilities in the country will achieve equal access to the services.

8.4.1.2 Attention given to persons with disabilities is cursory

A further examination of the seven health policy documents also indicates that the *Malawi National Sexual and Reproductive Health and Rights (SRHR) policy* and the *National Cervical Cancer Strategy* mention persons with disabilities but does not provide a detailed description of how the sexual and reproductive health needs of this vulnerable population group will be addressed.

The *Malawi National Sexual and Reproductive Health and Rights (SRHR)* policy aims to "provide a framework for provision of accessible, acceptable and affordable, comprehensive SRHR services to all women, men and young people of Malawi through informed choice to enable them attain their reproductive rights and goals safely", (Ministry of Health, 2017). To achieve the policy objective the SRHR policy has set up a number of priority areas, including family planning, maternal and neonatal health, sexually transmitted infections, HIV, and AIDS, reproductive cancers, infertility, young people in reproductive health, obstetric fistula and harmful practices or

domestic violence. These priority areas are to be addressed based on a human right principle, which states that;

> "All the people of Malawi shall have access to health services without distinction of ethnicity, gender, age, disability, sexual orientation, mental and health status, religion, political belief, economic, socio-cultural condition or geographic location", (Ministry of Health, 2017 , p.20).

However, even though the priority areas will be addressed based on these human right principles, none of the priority areas has a strategy that specifically targets persons with disabilities. For example, the priority area for family planning, intends to reduce unmet need for family planning through the provision of accurate and timely family planning information to all groups of people (Ministry of Health, 2017). The policy also aims to reduce the unmet need for family planning by increasing the coverage of family planning among young people. The two strategies may improve access of persons with disabilities to information on family planning services, but may at the same time, lead to the neglect of the specific needs of persons with disabilities. The family planning needs of persons with disabilities may be neglected because the information needs of persons with disabilities are different from those of persons without disabilities. Persons with disabilities need family planning information that is in braille or large print, whilst persons without disabilities may access the information in any other format (Ahumuza *et al.*, 2014; Mavuso and Maharaj, 2015). Therefore, the targeting of all persons in the community increases the vulnerability of persons with disabilities because their information needs are different from persons without disabilities.

The National Cervical Cancer Strategy also mentions persons with disabilities, but they are mentioned as part of the guiding principle on *respect for ethical principles of equity and justice.* Under this e*quity and justice principle*, the strategy aims to "ensure that cervical cancer control activities are universally accessible to the marginalized and at risk populations regardless of ethnicity, religion, political affiliation, disability, socio-economic status or geographic location", (Malawi Government, 2016). Apart from being mentioned in the equity and justice principle, persons with disabilities are not mentioned or explained in any of the other 6 priority areas of the strategy, which are; policy and advocacy; community awareness and mobilization; primary prevention with HPV vaccination scale up; secondary prevention screening and treatment of precancerous lesions; tertiary prevention: diagnosis and management pf cervical cancer cases and research, monitoring and evaluation. For example one of the strategies for primary prevention with HPV vaccination scale up, is to "enhance knowledge and promote behaviour change

interventions for reduction of risk of HPV infection and co-factors for cervical cancer development among the youth and the community.'' The target for youths in this strategy may also include young people with disabilities. However , compared to persons without disabilities, persons with disabilities, particularly those with mobility and sensory impairments have difficulties in detecting sexually transmitted infections due to their impairments which prevent them from noticing rashes or vaginal discharges or from feeling pain and itching (Nosek *et al.*, 2001). This inability to detect sexually transmitted infections increases their risk of cervical cancer. Therefore, it would have been better if the strategy had specifically targeted persons with sensory impairments because their health needs are different from other community members.

8.4.1.3   Specific Policy action identified to address the SRH needs of persons with disabilities

Despite receiving little attention in most of the health policies including the SRHR policy, persons with disabilities have been prioritised in the *National Youth Friendly Health Services Strategy* and the *National HIV and AIDS policy.* Both these documents have provided a detailed description of the strategies that will be used to address the sexual and reproductive health needs of persons with disabilities.

The *Malawi National Youth Friendly Health Services strategy* is a document that was developed following an evaluation of the Youth Friendly Health Services (YFHS) programme in 2014. The government of Malawi had begun a Youth Friendly Health Service programme in 2007 using the national YFHS standards which were adopted from the World Health Organization (Malawi Government, 2015). Between 2007 and 2013, no evaluation of the programme was conducted to examine the programme's effectiveness on the sexual and reproductive health quality of young people in the country (Feyisetan Bamikale et al, 2014). In 2014 the Reproductive Health unit of the Ministry of Health, with financial assistance from the United States Agency for International Development (USAID), decided to evaluate the YFHS programme by examining its effectiveness in responding to the needs of young people aged 10 to 24 (Malawi Government, 2015). The evaluation of the YFHS programme demonstrated that there was a low uptake of the YFHS among the intended population. Only a third of the young people in the communities had ever heard of YFHS programme and only 13% reported having ever used the services (Feyisetan Bamikale et al, 2014). These results prompted the Ministry of Health to develop the current *National Youth Friendly Health Services Strategy*.

The *National Youth Friendly Health Services Strategy* aims to "provide quality comprehensive integrated YFHS that are relevant, available, affordable, acceptable, accessible and appropriate, by all young people aged 10 to 24. The YFHS strategy acknowledges that young people with disabilities get lost in the wider programming of key populations and do not receive adequate

sexual and reproductive health care (Malawi Government, 2015). Young people with disabilities fail to access SRH services because of distance to the nearest health facility, operating hours, infrastructure and their reliance on others like their parents. The YFHS strategy intends to address these problems through targeted Social and Behavioural Change Communications; Outreach and door-to-door services; inclusive Comprehensive Sexuality Education (CSE); peer-to-peer approach for both youths and parents or guardians for promoting YFHS and alternative spaces and operating hours for the YFHS services.

With regards to the *National HIV and AIDS policy,* the policy intends to reduce the vulnerability to HIV infection among various population groups including persons with disabilities. The goal of the *National HIV and AIDS policy* is to " prevent the further spread of HIV infection, promote access to treatment for person's living with HIV and mitigate the health, social-economic and psychosocial impact of HIV and AIDS on individuals, families , communities and the nations", (Malawi Government, 2011). For persons with disabilities, the policy acknowledges that there are difficulties in the domestication of international instruments, which are aimed at reinforcing domestic responses to rights violations. This lack of enforcement makes victims of violations, such as persons with disabilities, left with no available remedies. To ensure that the rights of persons with disabilities are attained, particularly with respect to HIV and AIDS, the policy intends to empower and capacitate persons with disabilities, so that they can effectively participate in HIV and AIDS programs and policy development (Malawi Government, 2011). The *National HIV and AIDS policy* also intends to eliminate religious and cultural values and norms that promote stigma and discrimination towards persons with disabilities.

8.4.2   Inclusion of sexual and reproductive health needs of persons with disabilities in disability policies

 Apart from examining the inclusion of the sexual and reproductive health needs of persons with disabilities in Malawi's sexual and reproductive health policies, disability policies were also examined because they provide a framework for understanding the concept of disability and the needs of persons with disabilities.

Disability is not a new phenomenon in Malawi, issues concerning persons with disabilities started around the 1970s, when the Handicapped Persons Act was enacted in1971. The Enactment of the 1971 Handicapped Persons Act led to the establishment of the Malawi Council for the Handicapped (MACOHA) whose responsibility was to advise the government on all matters relating to the welfare, education, training and employment of the handicapped and to promote

public interest in the welfare and care of the handicapped persons (Malawi Government, 1971).

Between 1971 and the early 1990's, however, there was no development of either a policy

document or a strategy to guide the implementation of disability activities. It was only after the

country had adopted the *United Nations Standard Rules on the Equalization of Opportunities for*

Persons with Disabilities that a *National Disability policy* was drafted. This *National Disability*

Policy has not been enacted up to 2019 because of the need to make it compatible with the newly

enacted *Disability Act of 2012*. This lack of a national Disability policy has created problems for

stakeholders working on disability issues because they lack institutional guidance. To address this

institutional guidance gap, the Ministry of Gender, Children, Disability and Social Welfare in

collaboration with Disabled Persons Organizations (DPOs) developed the *National Policy on*

Equalization of Opportunities for Persons with Disabilities in 2006 (Malawi Government, 2006).

 The *Malawi National Policy on the Equalization of Opportunities* for persons with disabilities

aims "to promote the inclusion of persons with disabilities at all levels of society through the

creation of the enabling environment for the respect of human diversity, human rights and the

development of all human potential", (Malawi Government, 2006). The policy defines persons

with disabilities as;

> "any person who by reason of any impairment of the mind, sense or body, congenital or
> acquired, is unable to participate fully in regular education, occupation and recreation, or
> who, by reason of such impairment, requires special assistance or training to enable him
> or her to participate in regular, mainstream or inclusive education, occupation or
> recreation and other spheres of life", (Malawi Government, 2006).

 With regards to the sexual and reproductive health of person with disabilities, the policy only

focuses on the vulnerability to HIV and AIDS of persons with disabilities. According to the *Malawi*

National Policy on Equalization of Opportunities for Persons with Disabilities, persons with

disabilities are vulnerable to HIV and AIDS because they are presumed to have no sexual desires.

This assumption prevents persons with disabilities from having inadequate access to information,

health care and treatment. To address this HIV and AIDS related problem that persons with

disabilities face, the policy intends to increase the availability of knowledge about HIV and AIDS to

persons with disabilities This will be achieved through the Disabled Persons Organizations (DPOs)

that will disseminate information about HIV and AIDS. The policy also intends to empower

persons with disabilities to develop and maintain safer sexual and reproductive health practices

through the promotion of Voluntary Counselling and Testing (VCT) services (Malawi Government,

2006).

8.5 Results from Key informant interviews

To comprehensively understand the inclusion of the sexual and reproductive health needs of persons with disabilities in Malawi's policies and programmes, key informant interviews were conducted with the line ministries; the sexual and reproductive health unit and the planning department of the Ministry of Health and the disability department in the Ministry of Gender, Children, Disability and Social Welfare. Key informant interviews were also conducted with organizations that implement disability and sexual and reproductive health programmes in the country. A detailed list of these organizations has been given in section 8.2.2. The key informant interviews focused on the conceptual understanding and the sources of information or data that are used to develop disability or SRH policies and programmes. The study also focused on the challenges that the various organizations face when implementing disability inclusive sexual and reproductive health services. The following sections discusses the results obtained from the key informant interviews.

8.5.1   Conceptual understanding of disability used when developing disability and SRH policies and programmes

During the interview with key informants from various government departments and other organizations, participants were asked to provide a detailed description of the concept of disability that they use when developing policies and programmes. Examining the conceptual understanding of disability in the various departments was relevant in this study because it helps explain why some issues of disability are prioritised compared to others. An analysis of the information given during the interviews indicates that the conceptual understanding of disability is not the same in disability and sexual and reproductive health organizations. The Ministry of Health and the sampled SRH implementing organizations conceptualize disability in relation to the medical model, while the department of disability and the sampled disability implementing organizations conceptualize disability as a social problem or in relation to the social model of disability.

The conceptual understanding of disability also varies between the departments and organizations working on disability and those working on sexual and reproductive health. Among those working on disability (i.e. the disability department in the Ministry of Gender, Children, Disability and Social Welfare, MACOHA, DEWODE, Malawi Human Rights Commission and CBM), their conceptual understanding of disability relates to the negative interaction between a person

with an impairment and his or her physical, institutional or attitudinal environment, as illustrated in the following excerpt:

> "disability is a result of an interaction between the person with an impairment and the social barriers, the attitudinal barriers and the institutional barriers and all those factors in the society that limits the individual with an impairment from participating in social activities", (disability department, Ministry of Gender, Children, Disability and Social welfare).

For departments or organizations working on sexual and reproductive health, disability is conceived as an impairment or a condition that makes a person unable to function without assistance.

> *"Mmmm, disability in my understanding is a condition where one cannot be able to do some activities normally without assistance"*, (planning department, Ministry of Health)

This conceptual understanding of disability as an impairment or a condition, that limits a person's functions, is similar across all the sampled departments and organizations working on sexual and reproductive health. For example, Banja la Mtsogolo (BLM) perceives disability as a physical impairment. Family Planning Association of Malawi (FPAM) also understands disability as physical or mental impairment.

Unlike the Ministry of Health and the sampled populations working on SRH service provision, who have the same understanding of disability, the department of disability and the sampled disability organizations have some slight differences in their conceptual understanding of disability. For example, if the conceptual understanding of disability in the disability department is compared to that of MACOHA; it can be seen that there is a distinct difference in their understanding of disability. According to the MACOHA rehabilitation manager, disability in this agency is perceived as the presence of an impairment which affects the participation of an individual in a society, whilst the disability department in the Ministry of Gender, perceive disability as a social phenomenon or an environmental problem, that affect the participation of a person.

The conceptual understanding of disability of the sampled government departments and the implementing agencies, has affected their area of focus when developing or implementing policies and programmes. For example, the Ministry of health, particularly the reproductive health unit, understands disability as an impairment. This impairment perception has prevented them from having sexual and reproductive health programmes that specifically target persons with disabilities, as narrated by the key informant;

"I think they just have to use the services like anyone else. I don't think there is a need to target them specifically because they don't need a different service from any other person, for example, if a women who doesn't have a disability requires family planning services in the same way as a woman with disability may require family planning services. There is no difference in terms of the services that they can require. So I don't, I don't think they can be targeted in a special way", (Planning department, Ministry of Health).

For disability organizations like MACOHA, their conceptual understanding of disability has also affected their development and implementation of disability related programmes. Knowing that at MACOHA disability is perceived as presence of an impairment has made their Community Based Rehabilitation (CBR) Programme to specifically target those who have at least have a visible disability. In other words, they only focus on physical disabilities and rarely assists persons with mental problems, during their CBR service provision programmes.

8.5.2 Factors that guide in the development of disability and sexual and reproductive health policies and programmes

During the interviews, the participants were asked to discuss the sources of information that they use when developing disability or sexual and reproductive health policies and programmes. An analysis of the scripts using Nvivo 11.4 indicates that the sampled government departments and their implementing partners use both international and national documents as guidelines for policy and programme development. Data sources such as the Malawi Demographic and Health Surveys (MDHS) are rarely used in programme development, most organizations use stakeholder's consultative reports as their sources of data.

For the department of disability and its implementing partners, their source of information is mainly international recommendations and agreements such as the United Nation Convention on the Rights of Persons with Disabilities (CRPD). Reliance on international agreements is due to the fact that the country currently does not have a disability strategy to guide in the implementation of disability programmes. For example, the Christian Blind Mission (CBM) develops and implements its disability programmes using the CRPD and the Global federation strategy, which are both international documents. CBM uses these documents because Malawi consented to the convention, as explained in the following excerpt;

> *"As I said the Convention on the Rights of Persons with Disabilities is the key document for us and so we are saying, what does it say about persons with disability…, so we are guided by such documents by saying this is a Global issue, then we will also be looking at what Malawi is saying. Malawi has ratified the Convention, it means that they are agreeing with it".* (CBM, Lilongwe).

The Ministry of Health and its implementing partners on the other hand, rely on both international and national documents. Organizations such as FPAM and BLM not only use WHO recommendations but also national documents such as the *Health Sector Strategic Plan* and the *National Sexual and Reproductive Health and Rights strategy*. These organizations use national documents because they implement government sexual and reproductive health programmes.

> *"The services that we are providing now are in line with the government's established reproductive health strategy for the country. We are merely an implementing organization. The government has a roadmap for reproductive health and the strategy. The strategy has been developed over the years… We are not operating on our own, we are operating in line with the government strategies. So we are providing 60% of family planning services in Malawi. I would say over 80% of long acting and permanent methods. The government has decided to concentrate on short-term methods such as injectable, because they do not have the expertise, but with our teams, we are able to provide up to 60% to 80% of the long acting family planning methods",* (BLM, Lilongwe).

With regards to data sources, the Ministry of health and the sampled sexual and reproductive health service implementers (i.e. FPAM and BLM), use data that is collected from health facilities. This health facility data is centrally stored at the Ministry of Health's main library, called the *Health Management Information System*. The information collected from the health facilities only records a persons' age and the illness that they are suffering from at the time of the visit. No information about a person's disability is recorded, because of the assumption that making that sort of observation could be regarded as a discriminatory behaviour.

> *"The data sources are generalised, they do not necessarily record whether someone is blind or not. Even the registers, they just record whether you are a young person aged 10 to 24, and they categorise people by male or female. The registers do not indicate whether someone has a disability or not. If the registers were to record a person's disabling condition, then, I think it could probably be a mechanism of promoting discrimination",* (Reproductive Health Department, Ministry of Health, Lilongwe).

To supplement the information collected through the *Health Information Management System,* and to assess their performance in SRH provision and adherence to their Strategic plan, Banja La Mtsogolo (BLM) also collects its own data using exit interviews. The exit interviews are administered to both BLM service users and organizations that focus on persons with disabilities or gay populations. The exit interviews only provide information on how BLM has performed, they do not collect information on the sexual and reproductive health needs of the persons with disabilities.

The department of disability in the Ministry of Gender, Children, Disability and Social Welfare and the sampled implementing partners (i.e. CBM, MACOHA, DEWODE and Malawi Human Rights Commission) on the other hand, use data collected from both the population censuses or surveys and stakeholder consultations. To develop the *2006 National Policy on the Equalization of Opportunities for Persons with Disabilities*, the department of disability used data from the 1983 disability survey, the 2004 Living Conditions among people with Activity Limitations in Malawi survey (SINTEF study), and consultations with Disabled People's Organizations (DPOs) as illustrated in the following extracts;

> *"What led to the formation of the policy is the use of DPOs like APAM (Association of Persons with Albinism), Malawi Association for the Deaf and many others. So, at the beginning of it all, these stakeholders sat together and started identifying their needs. Together we came up with the areas of focus, which led to the development of what we called at that time the Utilization of Opportunities for persons with disabilities. This policy gives a proper direction to interventions dealing with persons with disabilities because they identified the areas of focus themselves",* (Disability department, Ministry of Gender, Children, Disability and Social Welfare, Lilongwe).

In as much as consultative meetings with disability organizations and disability data were used to develop the National policy on the *Equalization of Opportunities for Persons with Disabilities*, there were some limitations with the data sources used. The 1983 data was too old to address the sexual and reproductive health needs of the 21st century persons with disabilities. The 2004 SINTEF study also focused on access to health facilities, it did not comprehensively collect information the sexual and reproductive health needs of persons with disabilities.

Apart from the disability surveys, some of the sampled disability organizations, including DEWODE, use data collected from Community Rehabilitation Centres that are managed by

MACOHA, and case studies. For example, the Malawi Human Rights Commission, develop their programmes depending on the number of cases that have been reported to them concerning persons with disabilities, as illustrated this narrative;

> *"What I should say, is that we receive cases in a broader sense and some of the cases involve sexual and reproductive health. Right now there are a lot of sexual abuses in Balaka. This time we have received about 6 cases of persons with disabilities, cases like impregnation, others just getting married for I year and running away leaving the girl with a child , because the girl has got a disability and is very young. Now there is also a case in Balaka just close to Manjawira, a small girl who has an intellectual disability just got impregnated. The parents were suspecting a certain man and that man has also gone to court",* (Malawi Human Rights Commission, Lilongwe).

Nonetheless, the data collected by MACOHA, is limiting, because the organization only works in 14 of the 28 districts that exist in the country. The limited information poses some difficulties for organizations relying on this dataset because the dataset does not provide them with adequate information on the situation of persons with disabilities as explained by this key informant;

> *"We use the data that is there at the Malawi Council for the Handicapped (MACOHA), when we want to reach the communities. In some areas, we use social welfare data, we use Malawi Council for the Handicapped and other stakeholders including N.I.C.E. So when you hear the figures that are there, we see that we haven't reached a lot of women. Even, Malawi Council for the Handicapped, it has not reached the Whole of Malawi, it has reached only 14 districts. This means that there are more women that are left out there",* (DEWODE, Blantyre).

 The limited availability of disability data not only limits the coverage of disability programmes but also affects the actual implementation of the disability programmes as illustrated in the following excerpts;

> *"In Malawi disability information is very scarce, so there is really a big information gap. Sometimes, we are forced to plan interventions without any backing study or without evidence. I can say we do that. I can give you an example, in the past years we were lobbying for inclusion of persons with disabilities in technical colleges and we adopted Soche Technical College to be an example. We asked government to adopt other colleges,*

so that persons with disabilities can be going to those colleges. They gave us a figure, so for the first 2 years we were able to get persons with disabilities, no problem. The other years we were failing to reach our target. We discovered that we don't have as many persons with disabilities who are going to school, who qualify for technical colleges. So, we had to go all over the country, but we could not reach our target. That's one example where we see that we need a survey or a special census for persons with disabilities", (MACOHA, Blantyre).

The extracts from DEWODE and MACOHA, demonstrate how the limited availability of disability data in the country is affecting the implementation of disability programmes including the provision of sexual and reproductive health services.

8.5.3   Provision of sexual and reproductive health services to persons with disabilities

Key informants from the various departments and organizations were asked to discuss the sexual and reproductive health services that their organizations provide to persons with disabilities. A thematic analysis of the scripts indicates that the Ministry of Health and its sampled implementing partners do not provide sexual and reproductive health services that specifically target persons with disabilities. The department of disability in the Ministry of Gender, Children, Disability and Social Welfare and its sampled implementing partners on the other hand, do have programmes that focus on the sexual and reproductive health needs of persons with disabilities.

The Ministry of Health as the main health service provider in the country provides sexual and reproductive health services which include, maternal and new-born health, antennal services, treatment of sexually transmitted infections, HIV and AIDS counselling and treatment and cervical cancer screening (Ministry of Health, 2017). All these services are provided to the general population for free in government health clinics. The Ministry of Health expect persons with disabilities to access these services because they are also provided in local community clinics as illustrated in the following excerpts;

"For persons with disabilities, if it is contraceptives they need to get the information for contraceptives from the clinic and access them from there. If it is STI or HIV testing and counselling, they need to go and get the services from the health centre or clinic. If they are on ART or if they are supposed to be on ART they need to get the services on ART from the clinic. These services are accessed through that mechanism", (Reproductive health department, Ministry of Health, Lilongwe).

Both Family Planning Association of Malawi (FPAM) and Banja la Mtsogolo (BLM), also provide sexual and reproductive health services without considering the specific needs of persons with disabilities. FPAM provide sexual and reproductive health services to the general population, particularly those aged between 10 and 24. For young persons with disabilities, FPAM address their needs by constructing ramps in their clinics and ensuring that their health service providers are trained on how to obtain consent for youths with intellectual difficulties. Apart from these two interventions, they do not have specific services for persons with disabilities. Nor does Banja la Mtsogolo have specific SRH services for persons with disabilities. Nevertheless, BLM has realised that it is not adequately addressing the needs of persons with disabilities. Thus, it would like to develop SRH programmes that specifically target persons with disabilities; however, it does not have any role model (i.e. SRH service provider) in the country, who specifically targets persons with disabilities. To address this problem, BLM has started to send some of its SRH providers to Asia to learn about how they can best provide family planning services to persons with disabilities as indicated in the following narrative;

> *"I am just giving you the reality on the ground. It's not unique to BLM but across. volunteers who are working along with our frontline staff, even government health workers, the HSAs (Health Surveillance Assistants) do not have the knowledge and skill to counsel persons with disabilities. That's what we are trying to do, we are trying to learn from Asia and other countries, because in Malawi there is nobody who is providing Voluntary Counselling services to persons with disabilities. We want to pioneer it because we know it's not there, at community level as well as at facility level",* (BLM, Lilongwe).

The disability department and the sampled disability implementers, on the other hand, do want persons with disabilities to access sexual and reproductive health services. Their main challenge is that they cannot provide the services themselves because they are not mandated to do. To ensure that persons with disabilities have access to SRH services, they train SRH providers from government clinics and Banja la Mtsogolo on how they can mainstream disability issues in their programmes. The Department of Disability and its stakeholders also conduct awareness campaigns, to inform people on the sexual and reproductive health needs of persons with disabilities. For example, the Disabled Women in Development organization (DEWODE), conduct local community awareness campaigns, where they invite community leaders and family members of persons with disabilities.

> *"Yes, it's like when we go into the communities, we target like the HSAs, we target the Health Facilities, we target the chiefs, the communities, the families, the community as a whole. That's how we can empower them. In most cases persons who have intellectual or*

mental health, can understand issues better from their close family members or community members. So we go through those family members, we talk to the family members so that they should be on the know-how, on how they can assist persons with disabilities", (DEWODE, Blantyre).

The Malawi Council for the Handicapped (MACOHA), started to provide sexual and reproductive health services to persons with disabilities themselves, but the National AIDS Commission stopped them. To ensure that persons with disabilities still have access to information on sexual and reproductive health, the Council decided to use their Community Based Rehabilitations Programmes (CBR). Now they use the CBR programme to address the sexual and reproductive health needs of persons with disabilities.

"In HIV, we lobby SRH service organizations to provide HIV services to persons with disabilities. In the past we were providing some services ourselves, but NAC advised us to stop. NAC advised us to just lobby and orient service organizations, so that they can provide services to persons with disabilities, so that's what we are doing now. We have a special project where we are lobbying specifically, these service organizations on how to mainstream disability in their programmes. And now on Sexual and Reproductive Health, we don't really have special interventions as such, only that in our community based rehabilitation programmes we have organized meetings where we invite somebody from Banja la Mtsogolo or maybe a nurse from a hospital to talk about HIV, Sexual and Reproductive Health", (MACOHA, Blantyre).

From the above narratives, it can be deduced that Disabled People's Organizations would like persons with disabilities to access sexual and reproductive health services, but the Ministry of Health is not interested in providing SRH services that specifically target persons with disabilities. Thus, the disability department and its implementing partners need to increase their effort in lobbying the Ministry of Health to specifically target persons with disabilities.

To sum up, this chapter aimed to discuss the inclusion of the sexual and reproductive health needs of persons with disabilities in Malawi's disability and sexual and reproductive health policies and programmes. This study objective was accomplished through an analysis of policy documents using the Equiframe framework and thematic analysis of the key informant interviews using Nvivo 11.4 The results from the policy analysis have demonstrated that;

- Persons with disabilities are not included in the Malawi *National Health policy*, the *National Sexual and Reproductive Health and Rights strategy* and the *National Health Sector Strategic plan II*.

- The Malawi *National Sexual and Reproductive Health and Rights Policy (SRHR)* and the *National Cervical Cancer Control Strategy*, mention persons with disabilities, but do not provide a detailed analysis of their sexual and reproductive health needs, nor how the SRH needs will be addressed.

- Only the *National Youth Friendly Health Services Strategy* and the *National HIV and AIDS policy* address the sexual and reproductive health needs of persons with disabilities by providing specific policy actions that will be conducted to address the SRH needs of this sub-population group.

- The Malawi National Policy on the Equalization of Opportunities for Persons with disabilities also addresses the sexual and reproductive health needs of persons with disabilities but mainly focuses on their vulnerability to HIV and AIDS.

A thematic analysis of the key informant interviews has illustrated that:

- There are variations in the conceptual understanding of disability between government and non-governmental organizations working on sexual and reproductive health and those working on disability issues.

- Both national and international recommendations and agreements are used in the development and implementation of policies and programmes on disability and sexual and reproductive health.

- Nationally representative data sources such as the Demographic and Health Survey or disability surveys are rarely used in the development and implementation of disability inclusive sexual and reproductive health policies and programmes.

- The Ministry of Health and the sampled non-governmental organizations working on sexual and reproductive health do not have programmes that specifically target persons with disabilities, but the disability department in the Ministry of Gender, Children, Disability and Social Welfare and its implementing partners do have programmes that focus on the sexual and reproductive health needs of persons with disabilities.

8.6 Discussion of the results

The following paragraphs discusses the results obtained from the policy analysis of health and disability policies and key informant interviews in Malawi. The analysis has shown that there is little or no attention given to persons with disabilities in the *National health policy*, the National

Sexual and Reproductive Health and Rights Strategy and the *Health Sector Strategic Plan II*. These study findings correspond to Ivanova et al (2015) findings. Ivanova et al (2015) found that persons with disabilities were not mentioned in all the Sexual and Reproductive Health policies of the Republic of Moldova. In Ghana, the Adolescent Reproductive Health policy acknowledges persons with disabilities as one of the vulnerable population groups that needs special attention, but does not provide any strategies that could be used in addressing the needs of this sub-population group (Mprah, 2013).

Literature on the omission of or the lack of attention given to the sexual and reproductive health needs of persons with disabilities in health policies, has attributed this lack to inadequate disability data (WHO and World Bank Group, 2011). This has also be attributed to   non-involvement of persons with disabilities during the development of policies (ACFA, 2017) and the misconceptions about the sexual and reproductive health of persons with disabilities (WHO and UNFPA, 2009). Mprah (2013) has also associated the lack of attention given to persons with disabilities to the young population structures of most Sub-Saharan African region. The young population structures has resulted in policy makers focusing on young people rather than persons with disabilities or other sub-population groups (Mprah, 2013). The 2010 World Report on Disability has attributed the insufficient information on disability data to the lack of disability inclusive health policies, (WHO and World Bank Group, 2011). According to the report, most sub-Saharan Africa countries collect disability data that only focuses on severe disabilities and no other forms of disabilities. This practise leads to disability estimates that are less than 5% of the total population. The low disability estimates make policy makers view disability as a non-critical problem, and therefore not worth addressing in health policies.

In the case of Malawi, limited availability of data on the sexual and reproductive health needs of persons with disabilities and the rise in teenage pregnancy could be the contributing factors to the limited attention given to persons with disabilities in the sexual and reproductive health policies. In Malawi, there is limited information on the sexual and reproductive health needs of persons with disabilities. The representative surveys on disability that have been conducted in the country have focused on the living conditions of persons with disabilities including their access to general health services but not on their sexual and reproductive health needs. The current data source on persons with disabilities is the 2018 population and housing census, but the information on persons with disabilities is not very descriptive. Malawi is also a young population, with a projected proportion of 67% of people aged between 0 and 24 and a median age of 16.0 (NSO, 2010b). The 2015-16 Demographic and health survey, also reports that there is

an increase in teenage pregnancy from 26% in 2010 to 29 % in 2016. These estimates may explain why there are specific strategies for addressing the sexual and reproductive health of young people in both the *National health policy* and the *National Sexual and Reproductive Health and Rights policy* but not the SRH needs of persons with disabilities. The lack of attention to person with disabilities could also be due to the assumption that persons with disabilities do not contribute much to the population growth since there is no information about their fertility in the Demographic and Health Survey reports.

In addition to the limited information on the sexual and reproductive health needs of persons with disabilities, low awareness of disability or how it should be addressed, limited resources and or overall high levels of unmet needs could also be contributing to the limited attention given to the needs of persons with disabilities in the country's sexual and reproductive health policies. In Malawi as noted by Munthali (2011) and as observed from the key informant interviews   , there is an adequate legal environment for promoting and upholding the rights of persons with disabilities. The major problem is on how to address these human rights such as access to sexual and reproductive health needs since there is limited information on the sexual and reproductive health needs of persons with disabilities (Munthali, 2011). There is also limited involvement of persons with disabilities or their disability organizations during the development and implementation of policies on sexual and reproductive health services. The needs of persons with disabilities are also not prioritised in the country's policies and programmes because of limited resources and the overall high levels of unmet need. According to the 2015-16 Malawi Demographic and Health Survey, there is an overall 19% unmet need for family planning. This unmet need ranges from 16% among currently married women aged 45 to 49 and 22% among women aged 15-19. These high rates of unmet need among currently married women coupled with the limited resources presents difficulties for policy makers and programme developers to prioritise persons with disabilities even though they are amongst the most vulnerable population sub-group.

The study findings where the sexual and reproductive health needs of persons with disabilities, have been specifically targeted in the National Youth Friendly Health Services Strategy and the National HIV and AIDS policy are contrary to what was found in the health policy analysis study in Ghana. Mprah et al (2013) in their study on disability in sexual and reproductive health policies and research in Ghana, found that the National HIV and AIDS and STI policy did not mention persons with disabilities in any of its strategic areas. The study also found that although the Adolescent Reproductive health policy did mention young people with disability it did not provide a detailed description on how their needs will be addressed. The results observed in this study correspond to Mannan's et al (2011) study, where they found the HIV and AIDS policy of Malawi

to be of high quality in relation the health policies of Sudan, Namibia and South Africa. This means that the policy describes specific policy actions for addressing the needs of vulnerable populations including persons with disabilities and the intention to monitor the provision of services to persons with disabilities (Mannan *et al.*, 2011).

With regards to this study, the focus on the sexual and reproductive health needs of persons with disabilities in both the *National HIV and AIDS policy* and the *National Youth friendly Health Services strategy*, could be attributed to the high prevalence of HIV in the country. The HIV and AIDS prevalence of Malawi is one of the highest in the sub-Saharan Region. It is currently estimated at 8.8%, with the highest prevalence among women (10.8%) compared to men (6.4%) (NSO, 2016b). Apart from the HIV estimates, studies on HIV and AIDS among persons with disabilities in the country have also shown that persons with disabilities are at a higher risk of acquiring the HIV virus because they do not perceive themselves as being at risk of the virus (Munthali, Mvula and Ali, 2004). There is also a traditional belief in the country that if an HIV positive person has sexual intercourse with a person with a disability, the person gets cured (Mji et al 2008). Concerning the National Youth friendly health Services strategy, the focus on young persons with disabilities could also be attributed to the high rates of sexual abuse that are experienced by young people with disabilities, as reported by the Human Right Commission Officer in section 8.5.2and the 2014 evaluation report of Youth Friendly Health Services in Malawi.

The results on variations in the understanding of disability among those working on sexual and reproductive health and those working on disability issues support the assertion by researchers (like Altman. (2001), Edie et al (2005) and Mont. D (2007)) that disability is a complex phenomenon. The complexity of disability (leads to it being described from a range of perspectives including clinical, social, economic, socio-political, and administrative and human rights. According to Altman (2001)people working in the health sector base their understanding of disability "on the pathology that medical practitioners identify within the individual and prognosis that the practitioner expects relative to the type of condition and characteristic of the patient", (or the medical model of disability) (Altman, 2001). That is why those working in health service provision; perceive disability as an impairment or a health condition. The social perspective of disability on the other hand, stems from the experiences of persons with disabilities and the need for recognition of their human rights. The need for recognition as human beings make people with disabilities perceive disability as not only residing in the individual but also as a result of an interaction between the individual and the society (Gill, 1987). The need to

document the pathology by medical practitioners, and the need for recognition of basic human rights by persons with disabilities, helps explain why there are differences in the conceptual understanding of disability between the Ministry of health and its sampled implementers and the Department of Disability and its implementers.

The difference in the conceptual understanding of disability between the department of disability and the Malawi Council for the Handicapped (MACOHA) could be attributed to the Community Rehabilitation Programme that is being implemented by MACOHA. According to Khasnabis et al (2010), there have been some disagreements between DPOs and CBR programmes because CBR programmes were historically developed based on the medical model of disability due to the need for legitimatizing people for rehabilitation (Khasnabis *et al.*, 2010). Even though, CBR programmes currently aim at equalization of opportunities and the social inclusion of persons with disabilities, the historical context for the establishment of CBR programmes could be contributing to the conceptual understanding of disability of MACOHA (Khasnabis *et al.*, 2010; World Health Organization, 2015a). Thus the historical background may help explain why this study found a difference in the understanding of disability between MACOHA and the Department of Disability.

Apart from finding that there are differences in the conceptual understanding of disability, the study has also found that disability data is rarely used in the development and implementation of sexual and reproductive health policies and programmes. The limited use of disability data could be attributed to the methods used to collect the data. In Malawi, most of the disability data that is readily available is collected during the Population and Housing censuses. Population censuses focus on counting the total number of persons in the population and not on comprehensively collected sexual and reproductive health information. Thus, the disability information collected during population censuses is not sufficient to understand the sexual and reproductive health needs of persons with disabilities. Thus, the inadequate information creates difficulties in developing health policies and programmes because it does not adequately describe the extent of the sexual and reproductive health problems faced by persons with disabilities. This inadequacy of census data has also been observed by the World Health Organization (WHO) and the United Nations, as a result , the WHO has advised its member states to use the International Classification of Functioning, Disability and Health (ICF) framework in their disability data collection exercises (Madans, Loeb and Altman, 2011; WHO and World Bank Group, 2011) . The United Nations through the Washington Group on Disability Statistics has also developed a short set of questions to be used during population censuses or surveys, to help collect comprehensive disability data (Madans, Loeb and Altman, 2011).

The study has also found that the Ministry of Health and its implementing partners do not provide sexual and reproductive health services that specifically targets persons with disabilities. The non-provision of sexual and reproductive health services that specifically target persons with disabilities could be attributed to the policy guidelines and strategies that the Ministry of Health and its Implementing partners use in the development of their programmes. As discussed in section 8.4, the policy analysis result section, most of the health policies in the country, including the *National Sexual and Reproductive Health and Rights* strategy and the *National Sexual and Reproductive Health and Rights* (SRHR) policy, do not have strategies that specifically targets persons with disabilities. This lack of attention given to persons with disabilities in health policies could be hindering the Ministry of Health and its implementing partners from providing disability specific sexual and reproductive health services. This situation where the policy environment affects the provision of sexual and reproductive health services to persons with disabilities is not unique to Malawi. In the Philippines, the conservative socio-political context which discouraged public discussion of sexual and reproductive health services and the socio-religious stance of Hospital directors, hinder health service providers from providing sexual and reproductive health services to persons with disabilities (Lee *et al.*, 2015).

The results obtained from the thematic analysis of the health policies in the country and the key informant interviews also supports the proposed ICF framework of sections 2.6.2 and 2.7 of the thesis. In sections 2.6.2 and 2.7, the ICF frameworks proposes that access to sexual and reproductive health services among persons with disabilities may be influenced by environmental factors such as policy and institutional factors. From the policy perspective this study has found that only the National Youth friendly health Services strategy and the National HIV and AIDS policy have strategies that specifically target persons with disabilities. The limited availability of strategies for addressing the needs of persons with disabilities implies that programme developers have no guidance on how to address the sexual and reproductive health needs of persons with disabilities. Thus restricting persons with disabilities from accessing the sexual and reproductive health services. The limited availability of disability data and the difference in the understanding of disability among departments or organizations working on sexual and reproductive health provision and those working on disability programmes also supports the ICF framework by demonstrating there is limited provision of sexual and reproductive health services in the country because of limited availability of data on the sexual and reproductive health needs of persons with disabilities and difference in the understanding of disability.

8.7   Conclusion

In conclusion, this chapter aimed to examine the extent of the inclusion of the sexual and reproductive health needs of persons with disabilities in Malawi's sexual and reproductive health policies and programmes. This study objective was accomplished through an analysis of eight health and disability policies and strategies and key informant interviews. The results from this study have demonstrated that the sexual and reproductive health needs of persons with disabilities in the country are rarely addressed in health policy documents. The study has also found that there are variations in the conceptual understanding of disability between those working on disability issues and sexual and reproductive health service providers. Policy and programme developers in the country also rely on international and national agreements and recommendations when developing sexual and reproductive health policies and programmes, rather than disability data that is available in the country.

Even though there is limited information on the sexual and reproductive health of persons with the disability in the country, the limited information is not used in policy and programme development either because it does not provide sufficient information on the sexual and reproductive health needs of persons with disabilities or because it is too old. To address this data insufficiency problem, it is imperative that national representative disability surveys, focused on the sexual and reproductive health needs of persons with disability, should be conducted. Where there are limited resources, which may render the conduction of a special disability survey impossible, the current data sources (DHS and Housing and Population censuses) could use the UN Washington short set of questions or the WHO ICF framework to collect disability data on a comparative basis. This is because these instruments comprehensively measure the extent of the disability problem in the population. The collected disability information may assist policy makers and programmers to understanding the needs of persons with disabilities and why they need to be prioritised in national policies and strategies.

 Even though the study conducted a policy document analysis and key informant interviews to examine the inclusion of the sexual and reproductive health needs of persons with disabilities, the information gathered may not be the only method for examining disability-inclusive policies. A larger study could have also assessed the influence of the donor community in the formulation of disability inclusive health policies, but this was beyond the scope of the current research. Nonetheless, the findings from this study provide a large body of evidence for addressing the sexual and reproductive health needs of persons with disabilities.

9 Chapter 9: Conclusion and policy recommendations

9.1 Introduction

This study aimed to address the information gap on the provision of sexual and reproductive health (SRH) services to persons with disabilities by examining the link between measures of disability and access and utilization of sexual and reproductive health services in Malawi. This was premised on the understanding that persons with disabilities in Malawi and many other countries in sub-Saharan Africa continue to face challenges in accessing sexual and reproductive health services, despite the call of the 1994 International Conference on Population and Development (ICPD) Programme of Action (PoA) for universal access to sexual and reproductive health services. This study was also based on the 2006 United Nation's Convention on the Rights of Persons with Disabilities article 25, which calls for non-discrimination when providing sexual and reproductive health services. There is also limited information on the sexual and reproductive health needs of persons with disabilities (WHO and UNFPA, 2009; WHO and World Bank Group, 2011). This dearth of data has contributed to the development of SRH programmes that do not specifically target persons with disabilities and this situation consequently increases their vulnerability to sexual and reproductive health problems, including sexually transmitted infections. Therefore, it was considered imperative to examine how various measures of disability affect the uptake of sexual and reproductive health services among persons with disabilities in Malawi. These analyses are intended to provide reliable and evidence-based information for the formulation of target-specific interventions with which to address the sexual and reproductive health needs of persons with disabilities.

To examine the relationship between disability measures and uptake of sexual and reproductive health services, this study used the 2003 Malawi World Health survey (MWHS-2003) and the 2004 Malawi Demographic and Health Survey (MDHS-2004). The 2003 Malawi World Health survey, is a cross-sectional survey that was developed by the World Health Organization (WHO) to monitor health outcomes and health systems. The 2004 Malawi Demographic and Health survey, on the other hand, is a routine health survey that is developed by the Malawi National Statistics Office, to evaluate and enhance family planning initiatives in the country.

To address the study objectives using the 2003 MWHS and the 2004 MDHS, the study applied multiple logistic regression methods. Multiple logistic regression models were used to regress the dependent sexual and reproductive health service variables (current use of contraceptive

methods, assistance during delivery, place of delivery and HIV counselling) with the disability variables (impairment and functional limitation index). When regressing the sexual and reproductive health service variables by disability measures, socio-economic factors including age, sex, place of residence and level of education were used as control variables to ensure that the variation in uptake of SRH services is explicitly examined in relation to the disability measures.

Prior to the fitting of the multiple logistic regression models, Compound Hierarchical Ordered Probit Modelling (CHOPIT) was performed on the disability (functional limitation) index to examine the self-reporting of disability in Malawi. Research has shown that self-health assessments or self-reported measures, particularly those that involve the use of ordinal responses, are not comparable within and across sub-population groups (Salomon, Tandon and Murray, 2001; King *et al.*, 2004; Salomon, Tandon and Murray, 2004). Ordinal responses are not comparable due to differences in health expectations, interpretation of the self-assessment question, culture, level of education and sex of the respondent (King *et al.*, 2004; Salomon, Tandon and Murray, 2004). The focus of this study was on assessing the influence of health expectations on people's self-health evaluations in Malawi. It was envisaged that such an assessment would shed light on disability measurement issues in the country. The other objective was to determine the reliability of the disability tools that are used to measure disability or functional limitations because they contribute to the accurate estimation of the number of persons with disabilities.

In addition to examining the measurement of disability in the country, the study also explored the conceptual understanding of disability in the country. Research on disability has demonstrated that there are measurement issues related to disability because of the complexity of the disability concept. Disability as a concept is a complex phenomenon because its nature and severity depend on the socio-cultural context in which the person with the disabling condition or an impairment lives (Groce, 1999; Loeb, Eide and Mont, 2008). Therefore, to fully understand the measurement of disability and to link it to the uptake of sexual and reproductive health services, it was important for the study to explore the conceptual understanding of disability. The disability concept was also explored because it is the basis on which people identify themselves as having a disability and the basis which community members use when implementing policies and programmes at community level. To investigate the understanding of disability in Malawi, respondents from different sections of the society were approached to provide their viewpoints as regards to how disability is conceptualised.

The study also investigated the inclusion of the sexual and reproductive health needs of persons with disabilities in Malawi's health policies and programmes. Sexual and reproductive health policies were examined because they act as a roadmap to the provision of sexual and reproductive health services. The examination of the policies and programmes included a desk review and key-informant interviews. The policies included, the *2017-22 Malawi's National Sexual and Reproductive Health and Rights (SRHR) policy*; the *2015-2020 Malawi National Youth Friendly Health Services Strategy* and the *2011-2016 Malawi National HIV and AIDS policy*. Key informant interviews were conducted with policymakers and programme managers that are involved in the design, formulation and implementation of policies and programmes on disability and sexual and reproductive health services.

Results obtained from both the quantitative and qualitative component of this study provide input for this chapter which discusses ways for improving access and utilization of sexual and reproductive health services among persons with disabilities in Malawi. The chapter also highlights significant areas that need to be further explored to understand the link between the measurement of disability and the provision of sexual and reproductive health services. This chapter, therefore, aims to provide a summary of the results obtained from the quantitative and qualitative components of the study. Section 9.2 discusses the results based on the main objectives of the study. Section 9.3 further discusses the policy and programmatic implications of the study findings and recommends actions that need to be carried out to address the sexual and reproductive health needs of persons with disabilities. Section 9.4 discusses the limitations of the study followed by policy and academic contributions of the study in section 9.5.

9.2   Key study findings

This section discusses each of the main study objectives guided by the research questions.

9.2.1   How does peoples' perception of health states relate to the self-reported measurement of disability?

 An assessment of the self-reported measurement of disability in Malawi has shown that people in Malawi rely on their own understanding of health states to evaluate their functioning status. During the 2003 MWHS survey, the survey respondents were asked to evaluate their health state using the eight health domains of the ICF framework. The eight health domains are; mobility, self-care, pain and discomfort, cognition, interpersonal relationships, vision, sleep and energy and affect. Responses to the eight health domains were on a five-point scale: 1= none, 2 = mild, 3= moderate, 4= severe and 5= extreme or cannot do. In addition to the self-health evaluations, the

survey respondents were given five vignettes describing hypothetical individuals with varying degrees of functional limitations and were asked to evaluate the vignettes on a similar scale of 1 to 5.

Results obtained from the analysis of the vignettes shows that the survey respondents understood the various levels of difficulties described in the hypothetical stories. With regards to the self-assessment questions, this study has found that more than 60% of the survey respondents rated their functioning difficulty to be similar to that of the anchoring vignette with no functioning difficulties. By ranking themselves in relation to the vignette with no functional difficulty, the respondents were indicating that even though they understood that a disabling condition limits a person from carrying out his or her daily activities, they had no functional limitation, according to their own health expectations.

The results obtained from the relative ranking of the survey respondents corresponds to the proposition that when people are evaluating their own health state they do not only rely on their understanding of the research questions but also on their health expectations and experiences (Carr, Gibson and Robinson, 2001; Salomon, Tandon and Murray, 2004). According to Carr et al (2001) people who live with poor health are more likely to evaluate their health state as being in good condition, because they have low health expectations (Carr, Gibson and Robinson, 2001). People who live with good health on the other hand, are likely to evaluate their health state as being poor if they experience a minor illness because they have high expectations of their health (Carr, Gibson and Robinson, 2001). With regards to Malawi, research has shown that a high proportion of the population has low health expectations (Deaton and Tortora, 2015; Angwenyi *et al.*, 2018). A Gallup World Poll study on health and health care in twenty-eight sub-Saharan African countries including Malawi, Zimbabwe and South Africa, has reported that only 36% of people in Malawi have good health expectations (Deaton and Tortora, 2015). The low health expectations among the Malawian population has been attributed to poverty, experiences of drug-stock-outs in the health facilities, the poor attitude of health service providers and the likelihood of poor treatment outcomes (Munthali *et al.*, 2014; Angwenyi *et al.*, 2018). The poor health expectations that most Malawian people have, may explain why the survey respondents were ranking themselves as having no functional difficulties in carrying out their daily activities.

In addition to using unobserved health expectations, this study has also found that the presence of an impairment and the age of the respondents contributed to the self-health evaluations of survey respondents, even after correcting for shifts in category-cut-off points. The study has found that people with impairments are more likely to report experiences of difficulties in

carrying out their daily activities compared to people without impairments. Older people are also more likely to report functioning difficulties in all the eight-health domains compared to young people. Sex of the respondent, on the other hand, has been found to continue to be significantly associated with the reporting of functional difficulties in only cognition and self-care. For example, when it comes to the reporting of difficulties in concentrating or remembering things, men have been found to be less likely to report problems related to cognition problems in the Ordered Probit model. When the shifts in category cut-off points have been corrected, the likelihood of not reporting cognition problems among men has been found to remain significant. This finding suggest that men have good mental health compared to women.

The correction of shifts in category cut-off points has also been observed to change the significance and direction of the association between the socio-demographic variables and the health domains. For example, the direction of the association between sex and affect (or depression) has been found to change from a negative association to a positive association. This change in the association between self-reported disabilities and sex of the respondent after correcting for shifts in category cut-off points has also been observed in other developed countries such as the United States of America and Japan (Grol-Prokopczyk, Freese and Hauser, 2011; Tareque *et al.*, 2016). In Japan, Tareque et al (2016) observed that the significant association between the sex of the respondent and sleep-related problems disappeared after correcting for shifts in category cut-off points. In the United States, Grol-Prokopczyk et al (2011) also observed that the there was no statistically significant relationship between sex and the general self-rated health, after correcting for shifts in category cut-off points. According to Tareque et al (2016), the lack of a significant association between the sex of the respondent and self-reported disabilities, suggests that the health problems that women tend to report during population surveys may be less severe than reported. With regards to sub-Saharan Africa, little is known about the association between self-reporting and sex of the respondent after correcting for shifts in response category cut-off points. Therefore, it is not possible to conclude from the current study findings that the functional disabilities reported by the women were less severe than reported. Nonetheless, the findings from this study suggest the need for correcting for reported heterogeneity in self-health assessments in the region.

9.2.2 How is disability conceptualised in Malawi?

Having observed that the survey respondents were using their understanding of health states and health expectations to evaluate their functioning status, the study investigated the understanding of disability in Malawi. An investigation of the conceptual understanding of disability in some societies in Malawi has demonstrated that there is no single conceptual understanding of

disability in the country. When the study participants were asked what the term disability means to them or what comes to their minds when they think of disability, most study participants consistently failed to define disability. To respond to the disability question some participants mentioned different types of disabilities such as paralysis and blindness. These descriptions focused on the biological or medical aspect of disability. Other study participants responded to the disability question by providing factors that help them to identify persons with disabilities, such as a couple who fail to give birth after being married for several years. The descriptions given focused on the social aspect of disability. The responses given indicate that the biological and social context of the study participants helped them to conceptualise disability.

 The biological and social understanding of disability observed in Malawi is consistent with what was observed by Slikker (2009) in a large-scale survey in Ghana. Slikker (2009) studied the attitude of Ghanaian people towards persons with disabilities from November 2007 to May 2009 using structured and semi-structured questionnaires. From this study, it was observed that the study respondents had difficulty in providing a general description of the meaning of disability. To describe disability the respondents gave responses such as "someone who is crippled, dumb or deaf", or an inability to perform certain functions because of a problem with a part of the body (Slikker, 2009). The similarities in results observed from the Ghanaian study and the current study is interesting, considering the different study designs and samples. The Ghanaian study involved the use of structured and semi-structured interviews that were administered over a long period, whilst the current study was a cross-sectional study and used focus group discussions. The similarities in the study findings suggest that the lack of a single description of disability in Malawi is common to other countries in the sub-Saharan African region.

In addition to biological and social factors, the study has found that the cause of the disabling condition also contributes to the conceptualization of disability in Malawi. The causation aspect relates mainly to people's perception of mental illness. During the focus group discussions, study participants were asked if they perceived mental illness as a disability. Most of the respondents were sceptical in their perception of mental illness as a disability due to beliefs and perceptions that people have towards mental illness. In Malawi, mental illness or mental disorders are mainly attributed to witchcraft, alcohol and illicit drug abuse (Munthali, Mvula and Ali, 2004; Crabb *et al.*, 2012). Concerning witchcraft, there is a cultural understanding in the country that when people try to get rich through the use of traditional rites or sorcery they end up being mentally ill (Munthali, Mvula and Ali, 2004). With regards to alcohol and illicit drugs, a significant proportion of the population (95.7%) believe that excessive drinking of alcohol and the use of illicit drugs,

particularly marijuana ("Chamba"), lead to the development of mental disorders (psychiatric disorders) (Crabb *et al.*, 2012). The misuse of substances such as drugs or alcohol and the use of sorcery to get rich are perceived by the community members as moral failures (Gureje *et al.*, 2005). This belief of moral failure has translated to the notion of mental illness as being self-inflicted or carelessness and has resulted in the condemnation of persons with mental illness rather than understanding or sympathy (Munthali, Mvula and Ali, 2004; Gureje *et al.*, 2005).

The perception of mental illness that the community members have in the country suggests that knowledge about mental illness in the country is poor. The current study findings are consistent with what has been observed in other sub-Saharan African countries including Nigeria and Ghana (Gureje *et al.*, 2005; Barke, Nyarko and Klecha, 2011). In Nigeria, a multi-cluster survey on community knowledge and attitude to mental illness found that 80% of the sampled population selected drug and alcohol misuse as the main cause of mental illness and only 11.1% of the participants selected biological factors as the main cause (Gureje *et al.*, 2005). The similarity of the current study findings to those of Nigeria suggests that there is limited knowledge about mental illness across the sub-Saharan African region. This limited knowledge may have negative outcomes on the well-being of persons with mental illness; therefore, there is a need to intensify community awareness campaigns on mental illness.

Apart from investigating the community member's understanding of disability and mental illness, the study also inquired about the community member's perceptions of albinism. Information on persons with albinism was collected because persons with albinism have a skin pigment that is sensitive to the sun. Persons with albinism also have poor vision (Wan, 2003). The physical appearance and the visual impairment of persons with albinism have been found to expose persons with albinism to stigma and discrimination in both developed and developing countries (Wan, 2003; Baker *et al.*, 2010; Brocco, 2015). Therefore, it was imperative for the study to investigate the perception of community members towards persons with albinism. When the study participants were asked about their views on persons with albinism, most of the participants were of the view that persons with albinism have no disability, even though their skin pigment may look different from the rest of the community members. To reinforce the community member's positive attitudes towards persons with albinism, persons with albinism participated in the focus group discussion.

Research on persons with albinism in sub-Saharan Africa including Malawi has indicated that persons with albinism experience stigma and discrimination at the community level but not within the family setting (Braathen and Ingstad, 2006; Baker *et al.*, 2010; Cruz-Inigo, Ladizinski and Sethi, 2011; Brocco, 2015). The main reason for community member's stigma and discrimination has

been lack of awareness of albinism and failure to explain the cause of albinism. This study has observed that the participants had no negative attitudes towards persons with albinism. The positive attitude towards persons with albinism observed in this study could relate to the period at which the data for this study was collected. The qualitative data for this study were collected at the time when there were community and radio awareness campaigns on persons with albinism. Campaigns on persons with albinism were taking place in the country because of the abductions and killings of persons with albinism (Amnesty International UK, 2017; Adebayo, 2018). Persons with albinism were being abducted or killed for their body parts, because of the belief that the body parts of albinos are a source of wealth. Therefore, to alert the communities of the killing of albinos and to safeguard persons with albinism from abduction and being killed, the government through the assistance of some non- governmental organizations including the Norwegian embassy, were conducting awareness campaigns on persons with albinism. These awareness campaigns could have created understanding and sympathy towards persons with albinism and condemnation towards those who were killing persons with albinism. Therefore, it is not possible to conclude from the findings of this study that the sampled population do not discriminate against persons with albinism compared to other sub-Saharan African communities. The findings of this study can only highlight the impact of albinism awareness campaigns on people's perception of persons with albinism.

9.2.3   To what extent are functional limitation and impairment associated with the uptake of sexual and reproductive health services in Malawi?

Having assessed self-reported disability in Malawi, this study further analysed the association between impairment and functional measures of disability, and the uptake of sexual and reproductive health services. The results obtained from both multiple and multinomial logistic regression models indicate that presence of an impairment is not significantly associated with the uptake of modern contraceptive methods, HIV counselling services, place of delivery or professional health assistance during childbirth. The impairment findings observed in this study are contrary to what was observed by Mosher et al (2018) in their analysis of the Family Growth survey in the United States. Mosher et al (2018) found both physical and cognitive impairments (disabilities) to be significantly associated with the use of modern contraceptive methods (Mosher *et al.*, 2018). This difference in study findings could be related to the number of persons with impairments in the surveys. The current study only had 80 women who were observed to have impairments, whilst Mosher et al (2018) survey had 1444 women with either physical or cognitive impairments. The difference in study findings due to the sample size of women with impairments

necessitates the need for conducting a cross-sectional survey where women with impairments will be oversampled.

Even though the relationship between an impairment and use of modern contraceptive methods found in this study is different from what was observed in Mosher et al (2018) study; the non-significant variation in use of modern contraceptive has been observed in Uganda (Ayiga and Kigozi, 2016). Ayiga et al (2016) in their investigation of "Access to and uptake of contraception by women with disabilities", observed that the use of modern contraceptive methods among women with disabilities was similar to that of ever-married women. Ayiga et al (2016) attributed their study findings to the similarity in socio-cultural and structural barriers between women with disabilities and those without disabilities. Concerning this study, the non-statistically significant association could relate similarly in poor socio-economic status between women with impairments and those without impairments. The non-significant variation could also relate to the availability of Health Surveillance Assistants (HSAs) in the communities. Most rural communities in Malawi have Health Surveillance Assistants who provide basic health services including provision of short-term contraceptives (such as pills, condoms and injectables), HIV counselling and child-nutrition services (Kok *et al.*, 2016). The presence of the HSAs means that all women in the communities, whether with an impairment or no impairment, have access to the basic sexual and reproductive health services, thus reducing the variation in access between the two groups.

In addition to contraceptive use, this study has also found that there is no statistically significant variation in place of delivery and health professional assistance during childbirth between women with impairments and those without impairments. The non-significant variation in health professional assistance during delivery corresponds to what Redshaw et al (2013) found in their investigation on "experiences of maternity care during pregnancy among women with disabilities" in the United Kingdom (U.K). Redshaw et al (2013) found that there was no statistically significant variation in the timing of the first contact with a health professional about pregnancy care or in booking appointments, between women with physical or mental impairments and those without impairments. According to Redshaw et al (2013), the non-significant variation between women with impairments and those without impairments was an indication of how the health care system was starting to match the needs of women with impairments and those without impairments.

With regards to Malawi, the non-significant variation may be explained in relation to distance to the nearest health facility and the quality of health services received at the health facilities (NSO, 2005; Lohela, Campbell and Gabrysch, 2012; Leslie *et al.*, 2016). In most rural areas of Malawi, both women with disabilities and those without disabilities live 20 km away from the nearest

health facility (Munthali *et al.*, 2014). According to Lohela et al (2012), the odds of facility delivery in Malawi decrease by 65% for every 10 km increase in the distance to the closest facility. Since both women with and those without impairments live 20 km away from the nearest health facilities, this could explain why there is no significant variation in place of delivery. Nonetheless, other social and environmental factors could also be affecting the relationship between the presence of an impairment and place of delivery or assistance during delivery, but since this is beyond the scope of this study, there is a need to further explore factors that may contribute to the non-significant relationship between impairment measures of disability and place of delivery.

Apart from impairment measures of disability, this study also examined the association between functional limitation and uptake of sexual and reproductive health services. This study has found that functional limitation measures of disability are not significantly associated with the use of modern contraceptive methods, place of delivery and professional assistance during delivery, but are significantly associated with the use of HIV counselling services. This study has found that a unit increase in the level of functional limitation reduces the odds ratio of accessing HIV counselling services by a factor of (odds ratio=0.585). These study findings correspond to Abimanyi-Ochom et al (2017) findings in their study of "HIV and AIDS knowledge, attitude and behaviour of persons with and without disabilities ", in Uganda. Abimanyi-Ochom et al (2017) found that even though persons with functional difficulties had fewer days since last HIV test compared to those without functional difficulties, they were significantly less likely to return to the clinic for the HIV and AIDS results and counselling services (Abimanyi-Ochom *et al.*, 2017). The similarities in study findings between the current study and that of Abimanyi-Ochom et al (2017), which used the Washington short-set of questions, demonstrates the similarity in HIV and AIDS behaviour of persons with functional limitations in the sub-Saharan African region. The similarity in findings, therefore, necessitates the need to educate persons with functional limitations or functional disabilities on the importance of accessing HIV counselling services.

9.2.4   Are issues of disability incorporated in Malawi's sexual and reproductive health policies and programmes?

Having observed that functional limitations and impairment measures of disability are not significantly associated with uptake of sexual and reproductive health services in Malawi, the study investigated the country's sexual and reproductive health policies and programmes to further explore factors contributing to the low uptake of sexual and reproductive health services among persons with disabilities. An assessment of the sexual and reproductive health policies and

programmes through a desk review has demonstrated that there is minimal targeting of persons with disabilities in the country's sexual and reproductive health policy documents. Persons with disabilities have not been targeted or even mentioned in the *National Health policy,* the *National Sexual and Reproductive health and Rights strategy* and the *National Health Sector Strategic Plan II*. This study has found that the *National Sexual and Reproductive Health and Rights (SRHR) policy* and the *National Cervical Cancer strategy* provide a description of persons with disabilities but does not provide strategies that will be used to address the sexual and reproductive health needs of this sub-population group. It is only the *National Youth Friendly Health Service strategy* and the *National HIV and AIDS policy* that provides a detailed description of persons with disabilities and ways in which their sexual and reproductive health needs will be addressed.

The minimal targeting of persons with disabilities in the country's sexual and reproductive health policy documents correspond to what was found in Ghana by Kwadwo et al (2014). Kwadwo et al (2014) found the sexual and reproductive health needs of persons with disabilities to be cursorily mentioned or to be negatively targeted in four of the seven sexual and reproductive health policies and research documents in Ghana. According to Kwadwo, the need for controlling the reproductive behaviour of persons with disabilities and the perception that persons with disabilities do not contribute to the population growth, might have contributed to the minimal or negative targeting of persons with disabilities. In case of Malawi, this study explored, through a thematic analysis of key informant interviews, factors that may contribute to the minimal targeting of persons with disabilities in the country. These factors are differences in the perception of disability, lack of disability data and use of both national and international documents whose conceptual description of disability is different from the local understanding of disability.

There are differences in the perception of disability between the Ministry of Health and its implementing partners and the department of disability and its implementing partners. The ministry of health conceptualises disability as a medical problem whilst the department of disability and its partners conceptualise disability as a social problem. This difference in the perception of disability has led to the non-involvement of persons with disabilities or disability organizations during the planning and development of sexual and reproductive health policies and strategies. Persons with disabilities or their organizations are not involved in the development of health policies and strategies because the Ministry of Health perceives disability as a medical condition that needs to be addressed by medical professionals. This practice of not involving persons with disabilities during the development of SRH policies has also been observed in Uganda (ACFA, 2017) and Ghana (Kwadwo, Anafi and Sekyere, 2014), suggesting that it is a regional problem. Therefore, to ensure that the sexual and reproductive health needs of persons

with disabilities are addressed in the sub-Saharan African region's policies and reproductive health programmes; there is a need for the involvement of persons with disabilities or their organizations during the planning and development of sexual and reproductive health policies and programmes.

 Concerning the use of international and national documents for the development of health policies and programmes, this study has found that the department of disability and its implementing partners use international documents because the country does not have a disability strategy to guide in the development of programmes. Implementing partners for the Ministry of Health, on the other hand, use both WHO recommendations and the Health sector strategic plan because they perceive the documents as a roadmap to the provision of sexual and reproductive health services. The reliance of the disability and sexual and reproductive health organizations on international and national documents has implications on the implementation of SRH provision programmes. For example, CBM uses the United Nations CRPD as a key document in their planning and development of disability programmes, but the CRPD description of persons with disabilities is different from what this study has found from the focus group discussions with community members. The CRPD defines persons with disabilities as "those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (United Nations Human Rights Commission, 2012). The community members, on the other hand, perceive persons with disabilities as those with a physical anomaly, those who do not conform to societal expectations, people with mental illnesses, people with activity limitations and those who have unspecified illnesses. This difference in understanding of disability is likely to affect the implementation of sexual and reproductive health programmes that specifically target persons with disabilities because of differences in the identification of the target population.

With regards to disability data, this study has found that most of the data used in the development of the disability inclusive sexual and reproductive health policies are either outdated or do not reflect the sexual and reproductive health needs of persons with disabilities. A key informant interview with the department of disability in the Ministry of Gender, Disability and Social Welfare, has highlighted that the current national policy on the Equalization of Opportunities for Persons with Disabilities was developed based on the 1983 disability survey and the 2004 survey on Living conditions among people with activity limitations in Malawi. The 1983 disability survey is an outdated data source whose information may not relate to the current population of persons with disabilities. The focus of the 2004 survey, on the other hand, was on

estimating the proportion of persons with disabilities and not assessing the sexual and reproductive health needs of persons with disabilities. The implication of using these two data sources is that either the proportion of persons with disabilities may be underestimated due to the total population size at the time of the survey or the sexual and reproductive health needs of persons with disabilities are not clearly reflected due to the focus of the survey. Therefore, to ensure that there is an up to date disability database for policy development and that the available data clearly reflect the sexual and reproductive health needs of persons with disabilities, there is a need for conducting a disability survey whose focus will be on the sexual and reproductive health behaviour of persons with disabilities.

9.3   Research and policy recommendations

9.3.1   Are there disability measurement issues in Malawi?

An assessment of the self-reported measurement of disability in Malawi has shown that people in the country use their understanding of various health states and their individual health expectations to evaluate their functioning difficulties. A thematic analysis of the conceptual understanding of disability has also shown that there is no standardised definition of disability. This lack of a standardised definition of disability and the use of individual health expectations to respond to functional limitation questions demonstrate that there are disability measurement issues in the country that may affect the estimation of the number of persons with disabilities. For example, during a population census or survey, the survey respondents with a functionally limiting illness such as tuberculosis may report having no disability because they do not have a physical anomaly, whilst those with no children may report having a disability even though it may not affect their daily activities.

The likelihood of providing responses that do not tally with a disability question during population censuses or surveys supports Daniel Mont's evaluations of disability estimates in developing countries. According to Mont (2007), in developing countries where disability is perceived as a significant condition, "people who can walk around their homes but are incapable of walking to the market perceive their situation as not severe enough to be considered as a disability". As a result, they do not identify themselves as having a disability. To address this problem of the conceptual understanding of disability, Mont (2007) has proposed the use of functionally based measures of disability during censuses. This means that instead of asking respondents if they have a disability, respondents are asked about their inability to undertake activities or to participate in community activities. The proposed functionality approach has been employed in population surveys in some sub-Saharan African countries including Zimbabwe, Zambia and Malawi. This

approach has been found to be effective in capturing respondents who identified themselves as not having a disability but as having some functional limitations.

 With regards to Malawi, the current study has observed that there are still some problems with the use of functionally-based measures of disability to estimate the proportion of persons with disabilities. The current study has observed that people in Malawi still use their conceptual understanding of disability and their health expectations to respond to functional limitation questions. As a result, a high proportion (more than 60%) still report that they do not have functional limitations even though they may experience some limitations. Therefore, to improve the accuracy of disability estimates collected through the use of functionally based measures of disability, this study recommends the use of anchoring vignettes during population censuses or surveys. The anchoring vignettes should be formulated in such a way that they can standardise the differences in the conceptual understanding of disability among people of all age ranges, sexes and cultural beliefs or traditions. The formulation of standardised vignettes can be achieved by first conducting an exploratory survey, where people from various age groups and cultural beliefs will be asked to provide their conceptual understanding of disability.

9.3.2   Are measures of disability associated with the uptake of sexual and reproductive health services in Malawi?

An examination of the association between the measures of disability and uptake of sexual and reproductive health services in this study has shown that there is no statistically significant association between impairment and functional disabilities and the utilization of sexual and reproductive health services. The study has found that there is no variation in use of modern contraceptive methods, access of HIV counselling services, health facility delivery and health professional assistance during child-birth between women with impairments and those without impairments. With regards to functional disabilities, this study has also found that there are no variation in use of modern contraceptive methods, access to health facility delivery and health professional assistance during child-birth among women with various levels of functional limitations. Nonetheless, there is a significant association between the utilization of HIV counselling services and functional limitation status. A unit increase in functioning reduces the odds of accessing HIV counselling services. Following these study findings on the link between the measures of disability and uptake of sexual and reproductive health services the study recommends the following strategies;

Recommendation 1: Collection of disability and sexual and reproductive health data

To analyse the link between impairment and functional measures of disability, this study statistically matched the 2003 Malawi World Health Survey and the 2004 Malawi Demographic and Health survey data. The two datasets were statistically matched because of limited availability of data on the sexual and reproductive health of persons with disabilities in the country. The statistically matched dataset is likely to have influenced the study outcome, where there is a non-significant relationship between the measures of disability and the uptake of sexual and reproductive health services. This study, therefore recommends that a better detailed survey should be conducted on disability and sexual and reproductive health services. The data from the survey will then assists in analysing the link between the measures of disability and the uptake of sexual and reproductive health services. The survey should collect data on the number of persons with impairments and functional disabilities. The disability data should be disaggregated by individual characteristics such as age, sex, ethnicity and socio-economic status. To standardize the collected disability data and ensure that it is nationally and internationally comparable, the data should be collected based on the International Classification of Functioning, disability and Health (ICF) framework (WHO and World Bank Group, 2011). The disability data should also be collected in line with the recommendations from the United Nations Washington Group on Disability and the United Nations Statistical Commission (WHO and UNFPA, 2009; World Health Organization, 2011).

The collection of disability data in line with the United Nations Washington Group on Disability and the United Nations Statistical Commission is not a unique strategy in Malawi. Other disability surveys such the "2004 Living conditions among people with activity limitations" and the "2017 living conditions among persons with disabilities in Malawi", have also used the United Nations recommendations, particularly the United Nation Washington group short set of questions (Loeb and Eide, 2004; Eide and Munthali, 2018). The only difference between the surveys that have already been conducted in the country and the proposed survey is that the proposed survey will not only collect disability data but will also collect information on access and utilization of sexual and reproductive health services based on the individual and environmental components of the ICF framework (World Health Organization, 2002).

With regards to the individual and environmental components of the ICF framework, the survey should collect data or information on persons with disabilities' sexual and reproductive health such as number of births, place of delivery and use of contraceptive methods. The survey should further collect information on use of sexual and reproductive health care services, and social and environmental factors that influence access and utilization of sexual and reproductive health

services among persons with disabilities. The collected information will not only assists in analysing the link between the measures of disability and uptake of the sexual and reproductive health services, but will also provide information to help understand the factors that determine the sexual and reproductive health of persons with disabilities and guide in the implementation and monitoring of sexual and reproductive health care services.

Recommendation 2: Improve access to HIV services to women with disabilities

An analysis of the variation in use of HIV counselling services mong women with and without functional disabilities in this study has demonstrated that women with severe levels of functional disabilities are less likely to access HIV counselling services compared to women with no functional limitations. The implication of this study finding is that most women with functional disabilities are not aware of their HIV status compared to women with no functional disabilities since they do not access the HIV counselling services. This study therefore, recommends a number of strategies to be used to improve access HIV counselling services among women with functional disabilities. The first strategy is to map out the number of women with functional disabilities in both urban and rural areas. The mapping of women with functional disabilities can be conducted by representatives of Disabled People's Organizations (DPOs) such as Malawi Union for the Blind and the Association of Persons with Albinism in Malawi. Mapping of women with functional disabilities will help in estimating the number of women with functional disabilities. Some of the ways in which the mapping of women can be achieved may include; home visits where women with functional disabilities who can teach fellow women on HIV will be identified and encouraged to be trained as facilitators in the HIV awareness campaigns. With regards to women facilitators with limited communication, they can be trained on the Malawi sign language before training them about HIV. The trained facilitators can then be used to campaign and encourage fellow women with functional disabilities to access HIV counselling services. The facilitators with functional disabilities can then be equipped with information, education and communication (IEC) materials on HIV and other sexually transmitted diseases to use in their HIV counselling services campaign.

 The proposed strategy was piloted in Cambodia between 2008 and 2012 among deaf women (Bell, 2019,). The programme first estimated the number of deaf women through mapping. Then identified some capable deaf women who were first trained on the Cambodian sign language and then trained on HIV. This programme contributed to the increase in number of deaf women who were accessing HIV services (Bell, 2019,). Therefore, if this strategy can also be practised in

Malawi it is likely to assist in improving the HIV knowledge of functionally limited women, which will in turn increase the number of functionally limited women accessing HIV counselling services.

Recommendation 3: Training of the Ministry of Health staff about Disability

A thematic analysis of key informant interviews with policy makers and programmes developers working on sexual and reproductive health and disability in this study has demonstrated that the conceptual understanding of disability by those working in sexual and reproductive health, particularly those in the ministry of health is affecting the provision of sexual and reproductive health services to persons with disabilities. The ministry of Health staff understand disability as a medical problem or in view of the medical model. That they understand disability as a health condition that needs to be fixed or treated by the medical professionals. This understanding has led the ministry not to prioritise persons with disability in their development and implementation of sexual and reproductive health policies and programmes. Understanding that there is a high unmet need for sexual and reproductive health services among persons with disabilities compared to those without disabilities, this study recommends the training of the ministry of Health staff on disability.

The staff should be informed that even though persons with disabilities have health conditions that can benefit from medical care, but seeing disability as an individual problem may lead to the disregard of structural issues that negatively affect the sexual and reproductive health persons with disabilities (Shakespeare, Iezzoni and Groce, 2009). The structural issues may include poverty, environmental barriers such as lack of ramps at the health facility and social exclusion. The ministry of health staff should also be informed about the misconceptions about persons with disabilities that are held by most societies. The misconception may include the belief that persons with disabilities are not sexually active and thus do not require access to sexual and reproductive health services. To ensure that the staff are adequately trained and that the information given about disability improves their attitude towards persons with disability, persons with disabilities should also be recruited as members of staff at the Ministry. The presence of persons with disabilities in the ministry will help the members of staff to understand people with disabilities in context, appreciate their capabilities and challenge their negative attitude towards persons with disabilities. Further to the recruitment of persons with disabilities, when developing policies and programmes on sexual and reproductive health, the ministry should collaborate and share information with disability organizations such as the Federation of Disability Organizations in Malawi (FEDOMA).

9.4   Incorporating the ICF framework to the present study

This study has made use of the World Health Organization's ICF framework to study the link between the functional and impairment measures of disability and the uptake of sexual and reproductive health services in Malawi. In the review of frameworks used to study access to sexual and reproductive health services among persons with disabilities and the conceptualization of why persons with disabilities face difficulties in access sexual and reproductive health services, the Human rights based model and the ICF framework indicates that there is an interlinkage of body functions and structures with activity limitation and participation restriction which contributes to the challenges in accessing sexual and reproductive health services. The ICF framework has further demonstrates that the interaction between the disabling conditions and personal and environmental factors may also contribute to the limited accessibility of sexual and reproductive health services among persons with disabilities.

Due to the global concern of the quality of disability data that is collected in developing countries as stated in the 2010 World disability report and the need to collect disability data that is in-line with the ICF framework and is comparable across and within countries, this study examined the self-reporting of functional disabilities in the country (WHO and UNFPA, 2009; WHO and World Bank Group, 2011). The results obtained from the use of anchoring vignettes in this study, demonstrates that there are minimal to non-significant variations in the reporting of functional disabilities among people with different age and educational backgrounds in the country. These results implies that disability data that is collected in-line with the components of the ICF framework is comparable within countries. Thus the data can be used not only to study the functional disabilities of people in a particular population but also to compare the dsyfunctioning of people in various populations.

Further to the comparative nature of disability collected based on the ICF framework, this study has also demonstrated that the conceptualization of disability by the ICF framework particularly the components on body functions and structures, activity limitations and participation restrictions depicts the conceptualization of disability in a single social cultural context. For example, a focus group discussion on the understanding of disability in the rural and urban areas of Zomba and Blantyre districts of Malawi have shown that the understanding pf disability by the local community members is similar to that of the ICF framework. The community members in the sampled populations have indicated that they relate disability to a physical anomaly. This understanding is similar to that of body functions and structures of the ICF framework. The community members also understand disability as limitations in carrying out daily activities such

as walking to ones' workplace. The understanding of limitation in carrying out daily activities correspond to the activity limitation component of the ICF framework. This similarity in the conceptualization of the disability between the community members and the ICF framework confirms the assertion by the WHO that the ICF framework provides a common language for conducting disability research.

In addition to the provision of a common language for studying disability issues, this study also examined the link between the functional and impairment measures of disability and uptake of sexual and reproductive health services. Thus the study was investigating the link between the body function and structure, activity and participation components of the ICF framework and access and utilization of sexual and reproductive health services. The results obtained from this study indicates that there is no significant association between these three components of the ICF framework and the use of modern contraceptive methods, health facility delivery and professional health assistant during child-birth. These study findings may be as a results of the limited availability of data on the sexual and reproductive health of persons with disabilities. Therefore to draw a conclusive decision of the link between the body functions and structures, activity and participation components of the ICF framework and uptake of sexual and reproductive health services, there is a need for collecting data on disability and sexual and reproductive health.

Further to the assessment of the link between the body functions and structures, activity and participation component of the ICF framework and the uptake of sexual and reproductive health services, the study also investigated the influence of the environmental component of the ICF framework and the provision of sexual and reproductive health services to persons with disabilities. The results obtained from the policy analysis and key informant interviews indicates that the policy environment particularly the omission of the sexual and reproductive health needs of persons with disabilities in the country's sexual and reproductive health policies is contributing to the limited provision of sexual and reproductive health services to persons with disabilities. The difference in the conceptual understanding of disability and the lack of guidelines in the provision of sexual and reproductive health services to persons with disabilities have also been found to influence the provision of sexual and reproductive health services to persons with disabilities. These study findings support the assertion of the ICF framework that environmental factors such as policy environment and institutions influence the uptake of sexual and reproductive health services among persons with disabilities.

9.5   Strengths and limitations of the study

The current study examined the reporting of functional disabilities during population surveys in Malawi and the link between functional and impairment measures of disabilities and access and utilization of sexual and reproductive health services. Examining access and utilization of sexual and reproductive health services among persons with impairments and functional disabilities is important in population studies because it provides guidance to the achievement of the universal access to sexual and reproductive health services and the promotion of overall wellbeing. The results observed in this study suggests that there are no variations in access and utilization of sexual and reproductive health services between women with disabilities and those without disabilities. However, literature indicates that persons with disabilities experiences various challenges including structural and attitudinal challenges when accessing sexual and reproductive health services (Becker, Stuifbergen and Tinkle, 1997; Smith *et al.*, 2004; Ahumuza *et al.*, 2014). The difference in the results obtained in this study and what literature indicates demonstrates that there could be other sexual and reproductive health variables that could have a different relationship with impairment and functional disabilities. This could mean a different conclusion on the disability measures and sexual and reproductive health services relationship.

The current study's limitation in this regards is that there was no good dataset available on sexual and reproductive health and disability that could have been used to study the link between the measures of disability and sexual and reproductive health services. The limited availability of data made it necessary to use the matched dataset, which required lots of assumptions to be made and limited the generalizations of the results and power to see the associations. A matched dataset limits the generalization of the results and the power to see associations because it is influenced by confounding factors such as age or the socio-economic status of the matched samples (Faresjö and Faresjö, 2010; Leulescu and Agafitei, 2013).   Matching thus, increases the probability of concluding that there is no effect or no association between the dependent and independent variables when in fact there is an association (Faresjö and Faresjö, 2010). Nonetheless, statistical matching is one of the best techniques for studying population variables of interest when they have not been jointly observed. Statistical matching also helps in reducing high missing responses and improve response quality. Since this technique is rarely used in sub-Saharan Africa, this study therefore contributes to the methodological aspect of studying sub-population groups whose sexual and reproductive health information is rarely collected in the traditional surveys such as the demographic and health survey.

The other limitation of this study is that the data used for analysis was relatively old. To examine the reporting of functional disabilities and the link between disability measures and the sexual and reproductive health services, this study used the 2003 Malawi World Health Survey and the 2004 Malawi Demographic and Health survey. These two datasets were collected more than a decade ago, thus the perception of people towards various health states might have changed with the passage of time. The availability of sexual and reproductive health services such as antenatal services or professional health assistance could also have changed. Thus the use of such old datasets may have lead to the current results not truly reflecting the sexual and reproductive health behaviour of women aged between 18 and 49 with and without disabilities. However, in Malawi there is no current quantitative dataset on the sexual and reproductive health behaviour of persons with impairment or functional disabilities. The "2017 Living conditions among persons with disabilities in Malawi survey", does not provide any information on access to sexual and reproductive health services. The survey only reports that there are relatively small differences in the utilization of general health services between persons with disabilities and those without disabilities (77.1% and 78.6% respectively) (Eide and Munthali, 2018). The small difference in health service utilization reported in the 2017 Living conditions survey correspond to the current study findings. This similarity in findings lead to the conclusion that the current study findings are a true reflection of the sexual and reproductive health behaviour of women aged 18 to 49 who may or may not experience functional disabilities.

Further to the use of   an old and matched dataset, this study also did not assess the sexual and reproductive health behaviour of male participants. The sexual and reproductive health behaviour of men was not assessed in this study because the 2003 Malawi World Health survey did not collect the sexual and reproductive health history of male participants. By not studying the sexual and reproductive health behaviour of men, it meant that it is not feasible to generalize the results obtain from this study to all persons with disabilities. The results could not be generalized, because literature indicates that even though both men and women with disabilities experience challenges when accessing sexual and reproductive health services, there are some challenges that are exclusively experienced by men with disabilities (WHO and UNFPA, 2009; Ahumuza *et al.*, 2014; DeBeaudrap *et al.*, 2019). For example the WHO/UNFPA report on "promoting sexual and reproductive health for persons with disabilities", indicates that there are gender specific challenges that men with disabilities experience when accessing sexual and reproductive health services. Young men with mental and intellectual impairments fail to access the basic sexual and reproductive health information that women with intellectual impairment receive at home because of the misconception that they do not indulge in sexual relationships (WHO and UNFPA, 2009). In Uganda, Ahumuza et al (2014) also found men with disabilities failing to accompany

their wife to antenatal services because the health workers did not expect the men to attend antenatal care services (Ahumuza *et al.*, 2014). These sexual and reproductive health challenges experienced by men with disabilities necessitates the need to examine the variation in use of SRH services between men with disabilities and those without disabilities. Since this was beyond the scope of this study, it is recommended that further research should be conducted where the sexual and reproductive health history of men with and without disabilities will be collected and compared.

In addition to not studying the utilization of sexual and reproductive health services of men with and without disabilities, this study also did not include persons with disabilities in the focus group discussions. By excluding persons with disabilities in the focus group discussion, this study failed to collect and discuss the lived experiences of persons with disabilities. Discussing the lived experience of persons with disabilities is vital because they are the ones who experiences barriers when accessing sexual and reproductive health services (Shakespeare, 2013). The lived experiences of persons with disabilities could have improved the contribution of this study to disability research, by guiding policy makers and programme developers to develop policies and programmes that addresses the specific needs of persons with disabilities. However, in as much as collecting the lived experiences of persons with disabilities could have improved the contribution of this study to disability research, this was not the focus of this study. This study aimed at understanding the root cause of the negative attitudes of community members which hinders persons with disabilities from accessing sexual and reproductive health services. This was based on literature that indicates that the main challenges in accessing sexual and reproductive health services among persons with disabilities is the negative attitude of community members and health workers (Becker, Stuifbergen and Tinkle, 1997; Munthali *et al.*, 2017; DeBeaudrap *et al.*, 2019). The negative attitude of community members thus lead to the exploration of the conceptual understanding of disability among the community members and the community member's attitude towards persons with disabilities accessing sexual and reproductive health services.

9.6   Originality, academic and research area contribution of this PhD study

9.6.1   Research Originality

A review of the literature on access to sexual and reproductive health services among persons with disabilities in Sub-Saharan Africa including Malawi, has shown that most of the studies

conducted in the region have focused on assessing contextual factors that hinder or facilitate the utilization of SRH services among persons with disabilities. The studies have focused on effective HIV AND AIDS and reproductive health information to persons with disabilities (Munthali, Mvula and Ali, 2004) and (Mji et al 2008). Barriers to accessing sexual and reproductive health services (Smith *et al.*, 2004), (Mavuso and Maharaj, 2015) and (Ahumuza *et al.*, 2014) and experiences and perceptions of sexuality and HIV AND AIDS among young people with disabilities (Wazakili, Mpofu and Devlieger, 2006) and (Kassa *et al.*, 2016). The current study, on the other hand, has focused on linking disability and utilization of sexual and reproductive health services by examining the association between impairment and functional measures of disability and sexual and reproductive health services. The focus of this study on disability measures rather than on contextual factors means that it is a piece of independent and original research, since no other study in the region has focused on measures of disability.

9.6.2   Academic contribution

This study used anchoring vignettes and Compound Hierarchical Ordered Probit (CHOPIT) modelling tools to examine the self-reporting of disabilities in surveys in Malawi. The reviewed literature on self-reported disability has shown that few researchers in developing countries have attempted to examine the self-reporting of disability using both the anchoring vignettes and the CHOPIT model (Salomon, Tandon and Murray, 2004; King and Wand, 2007; Grol-Prokopczyk, Freese and Hauser, 2011; Hirve *et al.*, 2013). In this regard, the current study makes a methodological contribution to the academic world, by demonstrating how people in low-income countries self-evaluate their functioning status, through the use of statistical methods.

Further to the use of anchoring vignettes and the CHOPIT model, the study has also demonstrated how two distinct datasets can be statistically matched to create a dataset of variables that were not jointly observed. The technique of statistically matching two distinct datasets has been employed in developed countries like Germany (Simonson, Gordo and Kelle, 2012) and the United Kingdom (Rubin, 1986) to create datasets with a full-set of variables that are needed for drawing important inferences. This statistical technique is rarely employed in Sub-Saharan Africa countries, yet in these countries, there are limited datasets that have collected information on the sexual and reproductive health of marginalised populations such as persons with disabilities. The current study, therefore, contributes to the methodological approaches of studying the sexual and reproductive health needs of marginalised populations, including persons with disabilities.

9.6.3   Research area contribution

Despite claims that the socio-cultural context of a person influences the self-reporting of disability in developing countries, particularly the sub-Saharan African region   (Groce, 2006; Loeb, Eide and Mont, 2008) few attempts have been made to provide evidence for this claim.

The current study has contributed towards such claims by providing evidence on how the socio-cultural context of a person influences his or her self-health assessment. Variations in the understanding of various health states and health expectations have been shown to be significantly associated with the self-reporting for functional disabilities in Malawi. This result is significant for the development of research tools that are used to estimate the proportion of persons with disabilities in developing countries, particularly the sub-Saharan African region. In this regard, the current PhD provides a significant research contribution to disability research in Malawi and Africa.

 Apart from research tools, there have also been a number of studies in the sub-Saharan African region that have examined the challenges that persons with disabilities face when accessing sexual and reproductive health services, but few studies have focused on the impact of disability on access to sexual and reproductive health services. The analysis and results on the link between impairment, functional limitation and sexual and reproductive health services presented in this study fill a knowledge and information gap regarding the impact of disability on the uptake of sexual and reproductive health services. This is essential information for policies and programs as it provides input for target specific policy interventions.

 The current PhD results have further illustrated how the limited availability of disability data in the country is influencing the development and implementation of sexual and reproductive health policies and programmes that specifically target persons with disabilities. The study has shown how the non-availability of up-to-date disability data has contributed to the development of sexual and reproductive health policies that do not target persons with disabilities. The results of the study have also shown how the non-availability of disability data is affecting the implementation of disability-inclusive programmes especially those from MACOHA and DEWODE. Such information is a significant contribution of this PhD to the formulation and design of policies and programmes on disability and sexual and reproductive health service provision.

9.7 Personal Reflections on the PhD Study

Undertaking a PhD project can often be seen as an exciting experience but it can also be daunting. I have had the first-hand experience of carrying out a PhD project, and while it was generally an enjoyable experience, I did experience some challenges during the process. During the course of my PhD, I have increasingly realised that it was important to review current research studies on disability. However, because of limited information on disability research in Malawi, I had developed my research proposal based on the 2008 Malawi population and Housing census and the 2015 Malawi Demographic and Health Survey. The research proposal aimed to examine access to sexual and reproductive health services among persons with disabilities in Malawi by first examining the approaches used to estimate the disability prevalence in the country. Then examining the relationship between disability and sexual and reproductive health service utilization and finally to investigate the challenges faced by various group of persons with disabilities who utilize sexual and reproductive health services.

The process of reviewing other researchers' work, according to Kumer et al (2005) is called a literature survey and it helps a researcher to understand how far people in the field of interest have investigated the issue. Based on the use of the literature review or survey, I was able to understand the concept of disability and the various approaches used to measure disability. This knowledge helped me to develop my research objectives to the extent that I changed my first objective from examining the approached used, to exploring how disability is conceptualised and how its conceptualization influences the self-reported measurement of disability in Malawi. The literature survey also caused me to change my third study objective from examining challenges encountered by persons with disabilities to examining how issues of disability are incorporated when implementing inclusive sexual and reproductive health policies and programmes.

Regarding the conceptual understanding of disability, I learnt through the review of literature that there is no globally agreed-upon definition of disability and that the concept of disability itself is an abstract idea that has been evolving over time. Disability as a concept was first perceived as a medical phenomenon, then a social phenomenon and now it is perceived as a biopsychosocial phenomenon (World Health Organization, 2002; Whiteneck, 2006; WHO and World Bank Group, 2011). At the time of writing my PhD proposal, I had conceptualised disability as a physical anomaly due to the way it was measured in the 2008 Population and Housing census. Based on this disability measure, I had planned to examine only the sexual and reproductive health behaviour of persons who had problems with seeing or walking. After reviewing the literature on disability, I learnt that there were a number of approaches used for measuring disability including impairment and functional measures. In this regard, I decided to examine the sexual and

reproductive behaviour of persons with impairments and those with functional disabilities. However, I did not know that ordinal responses to abstract ideas like disability are not comparable within and across sub-population groups. It was from acting upon the advice of my supervisors to read Gary King, Christopher Murray and Joshua Salomon's work that I learnt about anchoring vignettes and the Compound Hierarchical Ordered Probit Model.

The use of anchoring vignettes and the CHOPIT model helped to strengthen the quantitative component of my PhD thesis and helped me realise that people in Malawi use their health expectations to evaluate their functioning status. Nonetheless, no researcher in the Social Statistics and Demography department had ever used the CHOPIT model. This meant that I had no reliable source to verify the accuracy of my study findings. Thankfully, Gary King (2004) and Sophia Rabe-Hesketh (2002) had uploaded on their websites the data samples that they had used to explain the modelling of data using the CHOPIT technique. These data samples helped me to verify the accuracy of the CHOPIT output.

In addition to having no reliable source for verifying the CHOPIT output, we realised in the middle of my first year, that there was no database or survey in Malawi that had jointly collected information on persons with disabilities and their sexual and reproductive health behaviour. This data deficiency was also managed through the assistance of one of my supervisors, who had faced a similar problem and had used statistical matching to address the problem. Fortuitously, my supervisor's data deficiency problem was within the same database, thus, he was able to use propensity score matching to pre-process the data for causal inference. Propensity score matching is a statistical technique which "allows a researcher to design and analyse an observational study so that it mimics some of the particular characteristics of a randomized controlled trial", (Austin, 2011). With regards to this study, I could not use propensity score matching, because the variables of interest were not jointly observed. To address this data deficiency problem, I had to read and learn a rarely used statistical matching technique that was developed by Marcello D'Orazio, a researcher at the Italian National Institute of Statistics.

The process of reviewing the literature to understand the concept of disability, learn statistical techniques such as Compound Hierarchical Ordered Probit modelling and statistical matching have made me appreciate the PhD learning process. During the course of my PhD, I have also come to understand the role of supervisors in the PhD project and this has improved my critical and analytical skills. I plan to use the skills gained during the course of this PhD to investigate the sexual and reproductive health behaviour of marginalised populations such as orphans and street children. The investigations will be comprised of a longitudinal survey of three to five years. The

survey will focus on young people aged between 15 and 18 years old. The orphans and the street children will be randomly sampled from the three main cities of Malawi that include Blantyre, Lilongwe and Mzuzu. At the initial stage of the survey, the research participants will be asked to provide their sexual and reproductive history and then they will be interviewed annually until the end of the research period. The information gathered from the orphans and the street children will be compared to that of children who live with their parents, to determine whether there are any significant differences in the utilization of sexual and reproductive health services between the two groups.

Appendix A   :Qualitative survey instruments

Appendix A1: Introductory letter from Chancellor College

PRINCIPAL
Prof. Richard Tambulasi, BA (Pub Admin), BPA (Hons), MPA, PhD.

CHANCELLOR COLLEGE
P.O. Box 280, Zomba, Malawi
Telephone: (265) 524 222
Fax: (265) 524 046
E-mail: principal@cc.ac.mw
popstudies@cc.ac.mw

9th October, 2017

To: The District Commissioner,
Zomba District Assembly,
P.O Box 23,
Zomba, Malawi

Dear Sir/Madam,
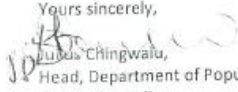
Letter of Introduction

i would like to introduce the bearer Monica Jamali who is conducting a study on "Disability and Sexual and Reproductive Health in Malawi", on behalf of the Department of Population Studies and the University of Southampton, United Kingdom. The overall objective of this study is to understand how the concept of disability is understood in relation to sexual and reproductive health and how this understanding is reflected in disability and sexual and reproductive health policies and programs in Malawi. The study intends to investigate local communities' views about people with disabilities and their sexual and reproductive health and people with disabilities' access and utilization of sexual and reproductive health services.

The study is being conducted in Zomba, Blantyre and Lilongwe. We therefore kindly request your assistance to assist the researcher and her team. In case you need further information, please contact the undersigned on 0888682263.

We sincerely thank you for your assistance.

Yours sincerely,

Julius Chingwalu,
Head, Department of Population Studies,
Chancellor College,
University of Malawi.

THE HEAD
POPULATION STUDIES
CHANCELLOR COLLEGE

0 9 OCT 2017

P O BOX 280
ZOMBA
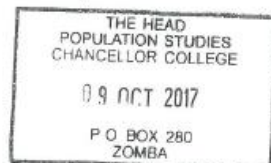
Appendix A

Appendix A2: **Introductory letter from Zomba City Council**

ZOMBA CITY COUNCIL

Your Ref:....................................

P.O. BOX 43
ZOMBA
MALAWI

Our Ref: ZCC/DM/ADMIN/27C

Tel.: (265) 01 525039
Fax.: (265) 01 525 362
E-mail:info@zombacitycouncil.org

10th October, 2017

TO WHOM IT MAY CONCERN

RE: PERMISSION TO CONDUCT ACADEMIC RESEARCH

Reference is made to the introductory letter from Head of Department, Chancellor College dated 10th October 2017 regarding the above captioned matter.

Permission is hereby granted to the bearer of this letter, **Monica Jamali**, a student at Chancellor College, to conduct academic research study on the topic of *Disability and Sexual and Reproductive Health in Malawi.*

Details of the conditions attached include:

   a) The participation must be voluntary
   b) Solely for academic purpose

Please assist her accordingly.

The under copied is being informed about this permission

1 OCT 2017

Davie Mlose
For: CHIEF EXECUTIVE

Cc: The Officer In- Charge, Zomba Police Station, Box 43, Zomba

ALL CORRESPONDENCES TO BE ADDRESSED TO THE CHIEF EXECUTIVE

Appendix A3: Participant Information Sheet (Focus-group)

Study Title: Disability Measurement and access to sexual and reproductive health services in Malawi

Researcher: Monica Zione Jamali

ERGO number: 30128

Please read this information carefully before deciding to take part in this research. It is up to you to decide whether or not to take part. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

Good morning/afternoon. My name is Monica Jamali. I am a student at the University of Southampton in the United Kingdom, studying a PhD in Social Statistics and Demography. I have come to this community to conduct a study on how the concept of disability is understood in relation to sexual and reproductive health and how this understanding is reflected in disability and sexual and reproductive health policies and programmes in Malawi. The study intends to investigate local communities' views about people with disabilities and their sexual and reproductive health. The purpose of this study is to help provide further understanding on how people understand the concept of disability and how it is included in sexual and reproductive health policies and programmes in Malawi. The findings will also provide input on how comprehensively disability could be measured, based on the conceptual understanding and its application in policy programmes such as HIV and AIDS. This study is sponsored by the Commonwealth Scholarship Commission and the Parkes Foundation.

Why have I been asked to participate?

You have been chosen to participate in this study because of your experience in accessing and utilizing sexual and reproductive health services.

What will happen to me if I take part?

 In this study you will be asked to discuss how you identify a person with disability, your thoughts about their disability in relation to their needs with a focus on sexual and reproductive health. You will also provide what you think is missing in the provision of services to people with disabilities especially in the area of sexual and reproductive health and why you think that way and propose how best you think people with disabilities can be supported with their sexual and reproductive health needs.

Appendix A

The discussion will take approximately 30 to 45 minutes. The discussion will be recorded and the information will be stored in a password protected computer accessible to the research team only. At the end of the discussion you will be given a small gift as a token of appreciation for your participation.

Are there any benefits in my taking part?

Although the collected information may not be beneficial to you as an individual, the results of the study may help the government and programme developers to formulate appropriate programmes and policies that will enable people with disabling conditions to access sexual and reproductive health services. The results may also help government in identifying appropriate resources to use when developing inclusive disability policies and programmes.

As a token of appreciation for your participation, you will each receive two bars of laundry soap (which is equivalent to the minimum wage) at the end of the discussion.

Are there any risks involved?

There is a minimal risk to your participation in this study because you will be asked to reflect on the sexual and reproductive health of people with disabilities. Therefore, if you think you will be uncomfortable to discuss the sexual and reproductive health of people with disabilities, feel free to withdraw and there will be no repercussion to your actions.

Will my participation be confidential?

Any information you provide in this study will be treated as confidential and your name will not be mentioned or associated with any result. The recorded information will be securely kept in a password protected computer and a locked storage device which will only be assessed by the research team. This research is under the approval of the University of Southampton Ethics Committee and in line with United Kingdom data protection laws, therefore be assured that the information you provide will be confidential, anonymised and stored in a safe place.

What should I do if I want to take part?

If you agree to take part in this study, you will be asked to sign a consent form as proof of your agreement. I will also ask you to provide information on your age, sex, education and marital status because they are important for analysing your views in the subject matter.

What happens if I change my mind?

You are also free to withdraw at any time when you feel uncomfortable to proceed without any penalty or negative effects. If you decide to withdraw in the middle of our discussion, you will be asked for permission to use the information gathered before your withdraw.

What will happen to the results of the research?

The information gathered from this research will be written up in a thesis and may be published as a research article. You may have a summary of our today's discussion or a summary of research findings once the project is completed if you wish. The findings from the completed project may be emailed to you or sent by post. Even though the anonymised research data will not be used for future projects once the project has been completed, the researcher will store the data in the University of Southampton repository for 10 years for review purposes and then the data will be destroyed.

Where can I get more information?

If you have any further questions or you need more clarifications about this study please contact the researcher on the following email address: mzj1g15@soton.ac.uk

What happens if something goes wrong?

If you have any concerns or complaints about this study please contact the University of Southampton Research Integrity and Governance Manager, on the following number 023 8059 5058, or email: rgoinfo@soton.ac.uk.

Thank you for taking your time to read this information sheet, we hope you will consider taking part in this research.

Appendix A

Appendix A4: Consent form (Focus-group)

Study title: Disability Measurement and access to Sexual and Reproductive health services in Malawi

Researcher name: Monica Jamali

ERGO number: 30128

Please initial the box(es) if you agree with the statement(s) :

I have read/listened to and understood the information sheet (Participation information sheet: Version 2, 17/09/2017; and have had the opportunity to ask questions about the study.	
I agree to take part in this research project and agree for my data to be used for the purpose of this study.	
I understand that my responses will be anonymised in reports of the research	
I understand my participation is voluntary and I may withdraw at any time for any reason without my rights being affected.	
I understand that the focus group discussion will be audio recorded.	

Data Protection

I understand that information collected about me during my participation in this study will be stored on a password protected computer and that this information will only be used for the purpose of ethically approved research studies.

Name of participant (print name)………………………………………………………………………

Signature of participant……………………………………………………………………………………….

Date…………………………………………………………………………………………..

Appendix A5: Focus Group discussion guide

Disability measurement and access to sexual and reproductive health services in Malawi

Date of Interview:	
Name of Interviewer:	
District Name:	
Village Name :	
Urban/ Rural:	
Number of male participants:	
Number of female participants:	

PARTICIPANTS DEMOGRAPHICS

Participant Number	Sex 1=Male 2=Female	Age in Years	Current marital status 1=Married or living together 2=Divorced/separated 3=Widowed 4=Never married and never lived together	Highest level of education attained 1=No education 2=Primary (standard 1 to 8) Secondary (form 1 to form 4) Tertiary (certificate, diploma , degree)
1				
2				
3				
4				
5				
6				
7				
8				
9				
10				
11				
12				

What is the research about?

Good morning/afternoon. My name is Monica Jamali. I am a student at the University of Southampton in the United Kingdom, studying a PhD in Social Statistics and Demography. I have come to this community to conduct a study on how the concept of disability is understood in relation to sexual and reproductive health and how this understanding is reflected in disability and sexual and reproductive health policies and programmes in Malawi. The study intends to investigate local communities' views about people with disabilities and their sexual and reproductive health. The purpose of this study is to help provide further understanding on how people understand the concept of disability and how it is included in sexual and reproductive health policies and programmes in Malawi. The findings will also provide input on how comprehensively disability could be measured, based on the conceptual understanding and its application in policy programmes such as HIV and AIDS. This study is sponsored by the Commonwealth Scholarship Commission and the Parkes Foundation.

Why have I been asked to participate?

You have been chosen to participate in this study because of your experience in accessing and utilizing sexual and reproductive health services.

What will happen to me if I take part?

 In this study you will be asked to discuss how you identify a person with disability, your thoughts about their disability in relation to their needs with a focus on sexual and reproductive health. You will also provide what you think is missing in the provision of services to people with disabilities especially in the area of sexual and reproductive health and why you think that way and propose how best you think people with disabilities can be supported with their sexual and reproductive health needs.

The discussion will take approximately 30 to 45 minutes. The discussion will be recorded and the information will be stored in a password protected computer accessible to the research team only. At the end of the discussion you will be given a small gift as a token of appreciation for your participation.

Are there any benefits in my taking part?

Although the collected information may not be beneficial to you as an individual, the results of the study may help the government and programme developers to formulate appropriate programmes and policies that will enable people with disabling conditions to access sexual and

reproductive health services. The results may also help government in identifying appropriate resources to use when developing inclusive disability policies and programmes.

As a token of appreciation for your participation, you will each receive two bars of laundry soap (which is equivalent to the minimum wage) at the end of the discussion.

Are there any risks involved?

There is a minimal risk to your participation in this study because you will be asked to reflect on the sexual and reproductive health of people with disabilities. Therefore, if you think you will be uncomfortable to discuss the sexual and reproductive health of people with disabilities, feel free to withdraw and there will be no repercussion to your actions.

Will my participation be confidential?

Any information you provide in this study will be treated as confidential and your name will not be mentioned or associated with any result. The recorded information will be securely kept in a password protected computer and a locked storage device which will only be assessed by the research team. This research is under the approval of the University of Southampton Ethics Committee and in line with United Kingdom data protection laws, therefore be assured that the information you provide will be confidential, anonymised and stored in a safe place.

What should I do if I want to take part?

If you agree to take part in this study, you will be asked to sign a consent form as proof of your agreement. I will also ask you to provide information on your age, sex, education and marital status because they are important for analysing your views in the subject matter.

What happens if I change my mind?

You are also free to withdraw at any time when you feel uncomfortable to proceed without any penalty or negative effects. If you decide to withdraw in the middle of our discussion, you will be asked for permission to use the information gathered before your withdraw.

What will happen to the results of the research?

The information gathered from this research will be written up in a thesis and may be published as a research article. You may have a summary of our today's discussion or a summary of research findings once the project is completed if you wish. The findings from the completed project may be emailed to you or sent by post. Even though the anonymised research data will not be used for future projects once the project has been completed, the researcher will store the data in the

Appendix A

University of Southampton repository for 10 years for review purposes and then the data will be destroyed.

Where can I get more information?

If you have any further questions or you need more clarifications about this study please contact the researcher on the following email address: mzj1g15@soton.ac.uk

What happens if something goes wrong?

If you have any concerns or complaints about this study please contact the University of Southampton Research Integrity and Governance Manager, on the following number 023 8059 5058, or email: rgoinfo@soton.ac.uk.

I will moderate the conversation and try to ensure that everybody gets a turn. Why don't we start by introducing ourselves [*Take time to write down their age, sex and educational status*]

Signature _____   Date _____

Section A: Understanding the concept of disability

 Now I would like to know more about this area. What long-term illnesses are common in this area?

1. Let's discuss the meaning of these disabling conditions (long-term illnesses) a little bit more. How do you understand the term disability?

Probes: a) Their understanding of disability, different types of disability (visible or invisible)

How do you know about disability?

Probe: Who provides you with information about disability? Did you make your own mind or is it decided by others? Do you consider people with albinism as having a disability?

2. Tell me about major challenges faced by people with disability. What are the main a) health problems; b) socioeconomic; c) other challenges?

Section B: Sexual and reproductive health of people with disabilities

3. Now I would like to discuss some delicate matters related to reproductive health and childbearing. What are your views on people with disability bearing children?

Probe: Reasons for their responses. Probe the views on people with disability having sex, using contraception. Ask hypothetical questions how they would react if someone with a visible disability came into their shop to buy condoms.

4. Now I want to find out about other people's attitudes towards people with disability and sexual and reproductive health. Do you think health providers treat people with disability the same way? What about pharmacies and shops where people buy condoms?

5. Now I want to ask about how the government and NGOs should provide sexual and reproductive health services for people with disability.

Do you think that there are enough services in your area that can help people with disability?

Probe: Enough services for people without sight? On wheel chairs? With mental health problems?

Should there be special services for people with disability?

Probe: Why? Or Why not?

Do you have any other thoughts or views you would like to share?

This marks the end of our discussion and I am going to turn the voice recorder off. Thank you very much for allowing me to discuss these issues with you

If you have any concerns, or think of additional information that should be shared, you can contact the researcher through the following contacts:

Ms Monica Jamali (researcher)

+44 7940 958996; mzj1g15@soton.ac.uk

You can also write to us at:

Department of Social Statistics and Demography

University of Southampton

Southampton

SO17 1BJ

Appendix A

Appendix A6: Participant Information Sheet (key-informant)

Study Title: Disability measurement and access to sexual and reproductive health services in Malawi

Researcher: Monica Zione Jamali

ERGO number: 30128

Please read this information carefully before deciding to take part in this research. It is up to you to decide whether or not to take part. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

Good morning/afternoon. My name is Monica Jamali. I am a student at the University of Southampton in the United Kingdom, studying a PhD in Social Statistics and Demography. I have come to your office to conduct research on how issues of disability are incorporated when implementing inclusive sexual and reproductive health policies. The aim of this study is to understand how disability is conceptualized and operationalized in sexual and reproductive health policies. The study will also gather information on factors that guide the formulation of such policies in various sectors of the government. Information on measures used to monitor inclusion of disability issues in sexual and reproductive health policies will also be collected. The research is sponsored by the Commonwealth Scholarship Commission and the Parkes Foundation.

Why have I been asked to participate?

You have been chosen to participate in this study because of your expertise and experience in programme development or policy formulation.

What will happen to me if I take part?

 If you agree to take part in this study, you will be asked questions on your understanding of disability and how disability is assessed when designing sexual and reproductive health policies, factors that guide the development of sexual and reproductive health policies, and the inclusion of disability issues in sexual and reproductive health policies. The discussion will take between 30 and 40 minutes. The discussion will be recorded with an audio recorder. Once transcribed, the information will be stored in a password protected computer and will not be accessed by any other persons apart from the research team. Your views to this research are very important and we hope that you will participate.

Are there any benefits in my taking part?

Although the collected information may not be beneficial to you as an individual, the results of the study may help the government and programme developers to formulate appropriate programmes and policies that will enable people with disabilities to access sexual and reproductive health services. The results may also help government in identifying appropriate resources to use when developing inclusive disability policies and programmes.

Are there any risks involved?

Your participation in this discussion is voluntary and there are no risks associated with your involvement.

Will my participation be confidential?

Any information you provide in this study will be treated as confidential and your name will not be mentioned or associated with any result. The recorded information will be securely kept in a password protected computer and a locked storage device which will only be assessed by the research team. This research is approved by the University of Southampton Ethics Committee the United Kingdom and also the University of Malawi.

What should I do if I want to take part?

If you agree to take part in this study, you will be asked to sign a consent form as proof of your agreement.

What happens if I change my mind?

You are also free to withdraw at any time when you feel uncomfortable to proceed without any penalty or negative effects on you. If you decide to withdraw in the middle of our discussion, you will be asked for permission to use the information gathered before your withdraw.

What will happen to the results of the research?

The information gathered from this research will be written up in a thesis and may be published as a research article. Even though the anonymised research data will not be used for future projects once the project has been completed, the researcher will store the data at the University of Southampton repository for 10 years for review purposes and then the data will be destroyed.

Where can I get more information?

If you have any further questions or you need more clarifications about this study please contact the researcher on the following email address: mzj1g15@soton.ac.uk

What happens if something goes wrong?

Appendix A

If you have any concerns or complaints about this study please contact the University of Southampton Research Integrity and Governance Manager, on the following number 023 8059 5058, or email: rgoinfo@soton.ac.uk.

Thank you for taking your time to read this information sheet, we hope you will consider taking part in this research.

Appendix A7: Consent form (Key-informant)

Study title: Disability measurement and access to sexual and reproductive health services in Malawi

Researcher name: Monica Jamali

ERGO number: 30128

Please initial the box (es) if you agree with the statement(s) :

I have read and understood the information sheet (Participation information sheet, Version 1, 17/09/2017; and have had the opportunity to ask questions about the study.	
I agree to take part in this research project and agree for my data to be used for the purpose of this study.	
I understand that my responses will be anonymised in reports of the research	
I understand my participation is voluntary and I may withdraw at any time for any reason without my rights being affected.	
I understand that my interview will be audio recorded.	

Data Protection

I understand that information collected about me during my participation in this study will be stored on a password protected computer and that this information will only be used for the purpose of ethically approved research studies.

Name of participant (print name)...

Signature of participant...

Date...

....

Appendix A

Appendix A8: Key Informant Interview guide for Civil Society or Non-governmental Organizations working on disability such as MACOHA and FEDOMA

DISABILITY MEASUREMENT AND ACCESS TO SEXUAL AND REPRODUCTIVE HEALTH SERVICES IN MALAWI

Name of department:

Date of Interview:

Position of person

Interviewed in the department:

Section of the department in which

Person interviewed works:

Responsibilities of Person

Interviewed:

Study aim: The aim of the study is to understand how disability is conceptualised within Malawi's policy and programmatic context. The study intends to understand the policy formulation process including how the policy was informed in terms of data and information with regard to inclusion of persons with disabilities.

Understanding the concept of disability and its inclusion in disability policies

1. Tell me about yourself and your work in this department. How long have you worked in this organization? Have you worked in any other department of this organization?
2. Now I would like to know about your understanding of disability. How do you understand disability?
   Probe: how is this understanding evidenced in your programmes or documents?

3. What forms of disabilities do you focus on?
   Probe: what are the reasons for focusing on these forms and why?

4. Let's talk about the activities that this organization implements. How were you informed about issues concerning people with disabilities when developing these activities?
   Probe: what was the goal? What data or information did you use? What was the reason

   for using such information?

5. How do you think your understanding of disability relate to these activities?
6. Are current sources of information about people with disabilities sufficient for your programmes?
   Probe: sources like Surveys and Censuses

7. Now consider the sexual and reproductive health of people with disabilities. What issues of disability do you think are specifically linked to the sexual and reproductive health of people with disabilities?
    Probe: why do you consider these issues? What of these issues does this organization implement and why?

8. What information gaps do you experience about people with disabilities with reference to their sexual and reproductive health?
    Probe: How can this gap be filled?

9. If your current budget was doubled (double the money) what would you do with regard to disability activities?
    Probe: would you do more of the same activities that you currently implement? Or would you do something different?

Is there something that you could add to what you have told me?

This marks the end of our discussion and I am going to turn the voice recorder off. Thank you very much for allowing me to discuss these issues with you.

If you have any concerns, or think of additional information that should be shared, you can contact the researcher   through the following contacts:

Ms Monica Jamali (researcher)

+44 7940 958996; mzj1g15@soton.ac.uk

You can also write to us at:

Department of Social Statistics and Demography

University of Southampton

Southampton

SO17 1BJ

Appendix A

Appendix A9: Key Informant Interview Guide for the Ministry of Gender, Children, Disability and Social Welfare

DISABILITY MEASUREMENT AND ACCESS TO SEXUAL AND REPRODUCTIVE HEALTH SERVICES IN MALAWI

Name of department:

Date of Interview:

Position of person

Interviewed in the department:

Section of the department in which

Person interviewed works:

Responsibilities of Person

Interviewed:

Study aim: The aim of the study is to understand how disability is conceptualised within Malawi's policy and programmatic context. The study intends to understand the policy formulation process including how the policy was informed in terms of data and information with regard to inclusion of persons with disabilities.

Understanding how disability is defined during the policy formulation process

1. Tell me about yourself and your work in this department. How long have you worked in this department? Have you worked in any other department of this ministry?

I have read the National Policy on the Equalization of Opportunities for Persons with Disabilities and it lists a number of issues that the policy addresses but I would like to understand:

2. What was the process that led to the identification of the issues in this policy?
   Probe: what was the goal? What data was used and why?

3. How do you understand disability?
   Probe: How is this understanding evidenced in the policy?

4. What forms of disabilities do you focus on?
   Probe: what are the reasons for focusing on these forms and why?

5. Let's talk about the sexual and reproductive health of people with disabilities. What issues of disability are specifically linked to the sexual and reproductive health of people with disabilities?
   Probe: why did you include these issues in the policy? How was your understanding of disability applied in this context?

6. How do you think the understanding of disability addresses issues or concerns of people with disabilities within the area of sexual and reproductive health?

7. How are these issues being implemented?

Probe: Are you satisfied with what is being implemented? What do you think could be done in the future to improve the issues that are being implemented?

Do you have any other information that you might want me to know?

This marks the end of our discussion. Thank you very much for your participation.

If you have any concerns, or think of additional information that should be shared, you can contact the researcher through the following contacts:

Ms Monica Jamali (researcher)

+44 7940 958996; mzj1g15@soton.ac.uk

You can also write to us at:

Department of Social Statistics and Demography

University of Southampton

Southampton

SO17 1BJ

Appendix A

Appendix A10: Key informant interview guide for the Ministry of Health and Population, OPC and Ministry of Finance and Economic Planning

Disability measurement and access to sexual and reproductive health services in Malawi

Name of department:

Date of Interview:

**Position of person
Interviewed in the department**:

**Section of department in which
Person Interviewed works**:

Responsibilities of Person

Interviewed:

Study Aim: The main aim of this study is to understand how disability is conceptualised and operationalised within Malawi's policy and programmatic frameworks. At a policy level, this study intends to understand the policy formulation process including how the policy was informed in-terms of data and information. It also seeks to understand how the policy is operationalised in-terms of its implementations by sector organizations.

Understanding how disability is defined and operationalised in policies

1. Tell me about yourself and your work in this department. How long have you worked in this department? Have you worked in any other department of this ministry?

I have read the sexual and reproductive health policy and it lists a number of activities that were undertaken to design the policy, but I would like to understand;

2. What was the process that led to the identification of the issues in this policy?
   Probe: what was the goal? What data was used and why?

3. How did you prioritise beneficiaries of this policy? Or who does this policy serve?
   Probe: Did this prioritization process consider special groups of people or vulnerable population groups such as people with disabilities? How is this reflected in the policy?

4. What issues about people with disabilities does the policy address?
   Probe: How did you identify these issues? What understanding of disability did you use?

5. How do you think the understanding of disability addresses issues or concerns of people with disabilities in this policy with respect to their sexual and reproductive health?

6. What sexual and reproductive health services/activities do you implement concerning people with disabilities?
   Probe: How were these activities identified and designed? What guided the inclusion of the activities in the policy?

7. How are these activities implemented in line with your understanding of the concept of disability?

8. Do you think this policy and the programmes in it do benefit people with disabilities?
   Probe: if yes, can you elaborate?

9. Is there some other information missing in the policy with respect to people with disabilities?
   Probe: why was this information missed? Is there anything being done about it?

Do you have any other additional information you think might be relevant to this study?

This marks the end of our discussion and I am going to turn the voice recorder off. Thank you very much for allowing me to discuss these issues with you. If you have any concerns, or think of additional information that should be shared, you can contact the researcher through the following contacts:

Ms Monica Jamali (researcher)

+44 7940 958996; mzj1g15@soton.ac.uk
You can also write to us at:

Department of Social Statistics and Demography

University of Southampton

Southampton

SO17 1BJ

Appendix A

Appendix 11: Key informant interview guide for Sexual and Reproductive Health policy implementing agencies including FPAM and Banja la Mtsogolo.

Disability measurement and access to sexual and reproductive health services in Malawi.

Name of department:

Date of Interview:

Position of person

Interviewed in the department:

Section of the department in which

Person interviewed works:

Responsibilities of Person

Interviewed:

Study aim: The aim of the study is to understand how disability is conceptualised within Malawi's policy and programmatic context. Particularly it aims to understand how the concept of disability is operationalised within sexual and reproductive health programmes in Malawi.

Understanding the operationalization of the concept of disability in sexual and reproductive health programmes

1. Tell me about yourself and your work in this department. How long have you worked in this organization? Have you worked in any other department of this organization?
2. Now I would like to discuss about the health services that this organization provides. What was the process that led to the identification of these services?
   Probe: what was the goal? What data or information was used? What were the reasons for using such data/information?
3. What policy guidance do you follow?
   Probe: Does this address sexual and reproductive health needs for people with disabilities?
4. Who does your service target? Or what is your target population?
   Probe: why did you target this population?

5. Do you provide sexual and reproductive health services to special groups of people or vulnerable populations such as people with disabilities?

6. What services do you provide to people with disabilities?

   Probe: How about sexual and reproductive health services? How did you identify these services?

7. Do you think that the health services you provide adequately addresses the sexual and reproductive health needs of people with disabilities?

   Probe: for example, people without sight? On wheelchairs? With mental health problems?

8. Do you think there is something missing in your provision of sexual and reproductive health services with reference to people with disabilities?

   Probe: why? What could be done to address these?

Is there something that you could add to what you have told me?

This marks the end of our discussion and I am going to turn the voice recorder off. Thank you very much for allowing me to discuss these issues with you.

If you have any concerns, or think of additional information that should be shared, you can contact the researcher through the following contacts:

Ms Monica Jamali (researcher)

+44 7940 958996; mzj1g15@soton.ac.uk

You can also write to us at:

Department of Social Statistics and Demography

University of Southampton

Southampton

SO17 1B

Appendix B: Results from CHOPIT model

B1: The following tables presents the linear assumption for age, level of education and wealth index.

Table 4.1: Estimated regression coefficients of the socio-demographic variables on self-reported mobility focusing on age

socio-demographic variable	Model 1: Age as a continuous variable (Ordered Probit model)		Model 2: Age in three formats (Ordered Probit Model)	
	β (95% CI)	P-value	β (95% CI)	P-value
Presence of an impairment vs no impairment	0.82(0.48-1.16)	<0.001	0.79(0.45-1.14)	<0.001
Rural vs Urban	-0.05(-0.29-0.19)	0.668	-0.05(-0.29-0.18)	0.653
Age (in years)	0.02(0.01-0.02)	<0.001	0.00(-0.04-0.04)	0.952
Age (Squared)			0.00(0.00-0.01)	0.266
36 and above vs 18 to 35 years			0.02(-0.34-0.38)	0.908
Male vs Female	-0.10(-0.27-0.08)	0.276	-0.09(-0.26-0.09)	0.318
Years of schooling	-0.01(-0.03-0.02)	0.529	-0.01(-0.03-0.02)	0.476
Wealth index	-0.11(-0.18--0.05)	0.001	-0.11(-0.18--0.04)	0.002

Table 4.2: Estimated regression coefficients of the socio-demographic variables on self-reported mobility focusing on education

socio-demographic variable	Model 1: Education as a continuous variable Ordered Probit model		Model 2: Education as continuous and categorical variable Ordered Probit Model	
	β (95% CI)	P-value	β (95% CI)	P-value
Presence of an impairment vs no impairment	0.82(0.48-1.16)	<0.001	0.78(0.44-1.13)	<0.001
Rural vs Urban	-0.05(-0.29-0.19)	0.668	-0.08(-0.32-0.17)	0.539
Age (in years)	0.02(0.01-0.02)	<0.001	0.02(0.01-0.03)	<0.001
Male vs Female	-0.10(-0.27-0.08)	0.276	-0.09(-0.27-0.08)	0.295
Years of schooling	-0.01(-0.03-0.02)	0.529	0.01(-0.03-0.06)	0.477
Level of education				
Less than primary vs No education			0.01(-0.29-0.31)	0.952
Primary vs No education			-0.23(-0.71-0.24)	0.333
Secondary and above vs No education			-0.43(-1.11-0.25)	0.214
Wealth index	-0.11(-0.18--0.05)	0.001	-0.11(-0.18--0.04)	0.001

Appendix B

Table 4.3: **Estimated regression coefficients of the socio-demographic variables on self-reported mobility focusing on wealth index**

socio-demographic variable	Model 1:Wealth index as a continuous variable		Model 2: Wealth Index as continuous and categorical variable	
	Ordered Probit model		Ordered Probit Model	
	β (95% CI)	P-value	β (95% CI)	P-value
Presence of an impairment vs no impairment	0.78(0.47-1.10)	<0.001	0.79(0.47-1.11)	<0.001
Rural vs Urban	0.02(-0.20-0.25)	0.854	0.03(-0.02-0.6)	0.823
Age (in years)	0.02(0.01-0.02)	<0.001	0.02(0.01-0.02)	<0.001
Male vs Female	-0.10(-0.26-0.07)	0.241	-0.10(-0.26-0.07)	0.246
Years of schooling	-0.01(-0.03-0.02)	0.538	-0.01(-0.03-0.02)	0.591
Wealth Index	-0.11(-0.17--0.04)	0.001	0.01(-0.07-0.09)	0.828
Wealth Quintile				
second vs lowest			-0.06(-0.31-0.19)	0.657
Middle vs lowest			-0.27(-0.53--0.01)	0.055
Fourth vs lowest			-0.23(-0.51-0.06)	0.121
Highest vs lowest			-0.51(-0.95--0.07)	0.022

B2: The following tables presents the effectiveness of accounting for reporting heterogeneity when assessing the self-reporting of functional disabilities, through a comparative analysis of the Ordered Probit and the CHOPIT model.

Table 4.2: Estimated regression coefficients of the socio-demographic variables on self-reported affect (depression) before and after correcting for shifts in category cut-off points.

Socio-demographic Variable	Before Correction (Ordered Probit Model)		After Correction (CHOPIT model)	
	β	P-value	β	P-value
Presence of an impairment vs no impairment	0.572	0.001	0.587	0.001
Rural vs Urban	-0.050	0.661	-0.137	0.251
Age (in years)	0.007	0.010	0.005	0.070
Male vs Female	-0.130	0.117	-0.065	0.450
Years of Schooling	0.013	0.253	0.006	0.586
Wealth index	-0.094	0.004	-0.102	0.003
Threshold 1 (None-Mild)				
Presence of an impairment vs no impairment			0.072	0.279
Rural vs Urban			-0.139	0.000
Age (in years)			-0.002	0.024
Male vs Female			0.080	0.007
Years of Schooling			-0.009	0.025
Wealth index			-0.010	0.368
Constant	0.467		0.533	0.003
Threshold 2 (Mild-Moderate)				
Presence of an impairment vs no impairment			-0.267	0.081
Rural vs Urban			0.350	0.000
Age (in years)			-0.001	0.680
Male vs Female			-0.058	0.305
Years of Schooling			0.005	0.479
Wealth index			0.019	0.393
Constant	0.975		-0.986	0.000
Threshold 3 (Moderate-Severe)				
Presence of an impairment vs no impairment			-0.003	0.983
Rural vs Urban			-0.044	0.580
Age (in years)			0.004	0.061
Male vs Female			-0.054	0.379
Years of Schooling			0.023	0.004
Wealth index			0.014	0.575
Constant	1.301		-1.220	0.000
Threshold 4 (Severe-Extreme)				

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Presence of an impairment vs no impairment		-0.046	0.654
Rural vs Urban		0.056	0.379
Age (in years)		0.004	0.019
Male vs Female		-0.131	0.004
Years of Schooling		0.006	0.320
Wealth index		-0.025	0.161
Constant	2.093	-0.530	0.000
Vignettes			
θ1		0.047	0.806
θ2		0.778	0.000
θ3		1.229	0.000
θ4		1.733	0.000
θ5		1.833	0.000

Table 4.2 Estimated regression coefficients of socio-demographic variables on self-reported pain and discomfort before and after correcting for shifts in category cut-off points

Socio-demographic Variable	Before Correction (Ordered Probit Model)		After Correction (CHOPIT model)	
	β	P-value	β	P-value
Presence of an impairment vs no impairment	0.825	0.000	0.805	0.000
Rural vs Urban	0.135	0.220	0.117	0.317
Age (in years)	0.012	0.000	0.010	0.000
Male vs Female	-0.005	0.947	-0.001	0.987
Years of Schooling	-0.004	0.672	-0.011	0.306
Wealth index	-0.064	0.023	-0.061	0.040
Threshold 1 (None-Mild)				
Presence of an impairment vs no impairment			0.002	0.979
Rural vs Urban			-0.016	0.756
Age (in years)			-0.003	0.035
Male vs Female			0.029	0.421
Years of Schooling			-0.008	0.097
Wealth index			-0.002	0.895
Constant	0.481		0.476	0.008
Threshold 2 (Mild-Moderate)				
Presence of an impairment vs no impairment			0.043	0.682
Rural vs Urban			0.010	0.883
Age (in years)			0.000	0.799
Male vs Female			-0.018	0.719
Years of Schooling			-0.001	0.848
Wealth index			0.006	0.728
Constant	1.118		-0.315	0.010
Threshold 3 (Moderate-Severe)				
Presence of an impairment vs no impairment			0.006	0.961
Rural vs Urban			-0.065	0.400
Age (in years)			0.002	0.214
Male vs Female			-0.093	0.099
Years of Schooling			0.016	0.036
Wealth index			0.019	0.370
Constant	1.615		-0.840	0.000
Threshold 4 (Severe-Extreme)				
Presence of an impairment vs no impairment			-0.082	0.374

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Rural vs Urban		0.188	0.005
Age (in years)		0.000	0.881
Male vs Female		-0.018	0.678
Years of Schooling		-0.005	0.393
Wealth index		0.005	0.738
Constant	2.899	-0.317	0.005
Vignettes			
θ1		0.073	0.705
θ2		0.993	0.000
θ3		1.434	0.000
θ4		1.997	0.000
θ5		2.369	0.000

Table 4.3 Estimated regression coefficients of socio-demographic variables on self-reported Cognition before and after correcting for shifts in category cut-off points

Socio-demographic Variable	Before Correction (Ordered Probit Model)		After Correction (CHOPIT model)	
	β	P-value	β	P-value
Presence of an impairment vs no impairment	0.576	0.000	0.490	0.002
Rural vs Urban	0.003	0.982	0.028	0.833
Age (in years)	0.010	0.000	0.008	0.003
Male vs Female	-0.298	0.001	-0.317	0.001
Years of Schooling	-0.021	0.090	-0.020	0.118
Wealth index	-0.040	0.222	-0.060	0.082
Threshold 1 (None-Mild)				
Presence of an impairment vs no impairment			-0.127	0.060
Rural vs Urban			0.008	0.861
Age (in years)			-0.002	0.108
Male vs Female			-0.024	0.461
Years of Schooling			0.001	0.767
Wealth index			-0.028	0.023
Constant	0.700		0.741	0.000
Threshold 2 (Mild-Moderate)				
Presence of an impairment vs no impairment			0.027	0.804
Rural vs Urban			0.165	0.044
Age (in years)			0.000	0.784
Male vs Female			0.006	0.910
Years of Schooling			-0.001	0.846
Wealth index			0.039	0.055
Constant	1.279		-0.763	0.000
Threshold 3 (Moderate-Severe)				
Presence of an impairment vs no impairment			0.196	0.055
Rural vs Urban			-0.180	0.018
Age (in years)			0.002	0.322
Male vs Female			-0.002	0.974
Years of Schooling			0.005	0.554
Wealth index			0.022	0.307
Constant	1.694		-0.760	0.000

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Threshold 4 (Severe-Extreme)			
Presence of an impairment vs no impairment		-0.007	0.937
Rural vs Urban		0.179	0.006
Age (in years)		0.000	0.885
Male vs Female		0.059	0.174
Years of Schooling		0.005	0.414
Wealth index		-0.010	0.528
Constant	2.898	-0.340	0.004
Vignettes			
θ1		0.200	0.360
θ2		0.938	0.000
θ3		1.618	0.000
θ4		1.863	0.000
θ5		2.402	0.000

Table 4.4. Estimated regression coefficients of socio-demographic variables on self-reported personal relationships before and after correcting for shifts in category cut off points

Socio-demographic Variable	Before Correction (Ordered Probit Model)		After Correction (CHOPIT model)	
	B	P-value	β	P-value
Presence of an impairment vs no impairment	0.404	0.022	0.447	0.019
Rural vs Urban	0.289	0.043	0.265	0.079
Age (in years)	0.012	0.000	0.009	0.003
Male vs Female	0.095	0.304	0.125	0.205
Years of Schooling	0.004	0.732	0.000	0.973
Wealth index	-0.027	0.439	-0.022	0.564
Threshold 1 (None-Mild)				
Presence of an impairment vs no impairment			0.074	0.380
Rural vs Urban			-0.001	0.983
Age (in years)			-0.003	0.063
Male vs Female			0.035	0.382
Years of Schooling			-0.007	0.189
Wealth index			0.005	0.728
Constant	1.555		1.557	0.000
Threshold 2 (Mild-Moderate)				
Presence of an impairment vs no impairment			-0.206	0.211
Rural vs Urban			-0.201	0.023
Age (in years)			0.002	0.388
Male vs Female			-0.042	0.550
Years of Schooling			0.025	0.012
Wealth index			0.007	0.789
Constant	2.110		-0.755	0.000
Threshold 3 (Moderate-Severe)				
Presence of an impairment vs no impairment			-0.177	0.255
Rural vs Urban			-0.205	0.012
Age (in years)			0.003	0.256
Male vs Female			0.054	0.410
Years of Schooling			-0.007	0.450
Wealth index			0.007	0.775
Constant	2.546		-0.746	0.000

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Threshold 4 (Severe-Extreme)			
Presence of an impairment vs no impairment		0.000	0.998
Rural vs Urban		0.186	0.004
Age (in years)		0.000	0.996
Male vs Female		-0.079	0.069
Years of Schooling		-0.005	0.387
Wealth index		-0.029	0.073
Constant	3.081	-0.208	0.088
Vignettes			
θ1		1.067	0.000
θ2		2.263	0.000
θ3		2.802	0.000
θ4		3.007	0.000
θ5		3.053	0.000

Table 4.5 Estimated regression coefficients of socio-demographic variables on self-reported sleep and energy before and after correcting for shifts in category cut-off points

Socio-demographic Variable	Before Correction (Ordered Probit Model)		After Correction (CHOPIT model)	
	B	P-value	β	P-value
Presence of an impairment vs no impairment	0.170	0.313	0.192	0.292
Rural vs Urban	-0.150	0.225	-0.229	0.086
Age (in years)	0.012	0.000	0.010	0.001
Male vs Female	-0.071	0.407	-0.009	0.924
Years of Schooling	-0.004	0.755	-0.019	0.128
Wealth index	-0.032	0.312	-0.031	0.371
Threshold 1 (None-Mild)				
Presence of an impairment vs no impairment			0.020	0.820
Rural vs Urban			-0.057	0.337
Age (in years)			-0.003	0.045
Male vs Female			0.053	0.201
Years of Schooling			-0.017	0.002
Wealth index			0.001	0.952
Constant	0.837		0.845	0.000
Threshold 2 (Mild-Moderate)				
Presence of an impairment vs no impairment			0.060	0.654
Rural vs Urban			-0.076	0.393
Age (in years)			0.001	0.757
Male vs Female			0.041	0.531
Years of Schooling			0.011	0.222
Wealth index			-0.008	0.735
Constant	1.432		-0.667	0.000
Threshold 3 (Moderate-Severe)				
Presence of an impairment vs no impairment			-0.104	0.427
Rural vs Urban			-0.170	0.029
Age (in years)			0.003	0.130
Male vs Female			-0.076	0.206
Years of Schooling			0.018	0.028
Wealth index			0.015	0.509
Constant	1.808		-0.744	0.000
Threshold 4 (Severe-Extreme)				

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Presence of an impairment vs no impairment		0.112	0.196
Rural vs Urban		0.101	0.129
Age (in years)		-0.001	0.338
Male vs Female		0.012	0.777
Years of Schooling		-0.012	0.030
Wealth index		0.001	0.953
Constant	2.874	-0.027	0.817
Vignettes			
θ1		0.256	0.251
θ2		1.600	0.000
θ3		1.769	0.000
θ4		1.902	0.000
θ5		2.289	0.000

Table 4.6: Estimated regression coefficients of socio-demographic variables on self-reported vision before and after correcting for shifts in category cut-off points

Socio-demographic Variable	Before Correction (Ordered Probit Model)		After Correction (CHOPIT model)	
	B	P-value	β	P-value
Presence of an impairment vs no impairment	0.568	0.001	0.546	0.002
Rural vs Urban	-0.177	0.228	-0.283	0.069
Age (in years)	0.021	0.000	0.019	0.000
Male vs Female	-0.052	0.597	0.043	0.678
Years of Schooling	-0.014	0.300	-0.032	0.027
Wealth index	-0.062	0.086	-0.059	0.121
Threshold 1 (None-Mild)				
Presence of an impairment vs no impairment			-0.029	0.714
Rural vs Urban			-0.116	0.040
Age (in years)			-0.002	0.117
Male vs Female			0.110	0.005
Years of Schooling			-0.020	0.000
Wealth index			0.002	0.870
Constant	1.344		1.356	0.000
Threshold 2 (Mild-Moderate)				
Presence of an impairment vs no impairment			0.124	0.352
Rural vs Urban			0.093	0.363
Age (in years)			-0.001	0.529
Male vs Female			-0.063	0.358
Years of Schooling			0.003	0.741
Wealth index			0.011	0.659
Constant	1.820		-0.761	0.000
Threshold 3 (Moderate-Severe)				
Presence of an impairment vs no impairment			-0.022	0.861
Rural vs Urban			-0.002	0.985
Age (in years)			0.004	0.070
Male vs Female			-0.088	0.164
Years of Schooling			0.035	0.000
Wealth index			-0.006	0.794
Constant	2.349		-0.966	0.000
Threshold 4 (Severe-Extreme)				

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Presence of an impairment vs no impairment		-0.168	0.077
Rural vs Urban		0.032	0.629
Age (in years)		0.001	0.315
Male vs Female		-0.066	0.138
Years of Schooling		-0.007	0.233
Wealth index		-0.006	0.709
Constant	3.274	-0.080	0.532
Vignettes			
θ1		0.950	0.000
θ2		1.482	0.000
θ3		2.560	0.000
θ4		2.678	0.000
θ5		3.330	0.000

Table 4.7 Estimated regression coefficients of socio-demographic variables on self-reported self-care before and after correcting for shifts in category cut-off points

Socio-demographic Variable	Before Correction (Ordered Probit Model)		After Correction (CHOPIT model)	
	B	P-value	β	P-value
Presence of an impairment vs no impairment	0.560	0.000	0.538	0.001
Rural vs Urban	0.162	0.278	0.261	0.091
Age (in years)	0.016	0.000	0.015	0.000
Male vs Female	-0.229	0.018	-0.262	0.009
Years of Schooling	-0.005	0.710	0.008	0.590
Wealth index	-0.041	0.253	-0.055	0.143
Threshold 1 (None-Mild)				
Presence of an impairment vs no impairment			-0.030	0.646
Rural vs Urban			0.113	0.019
Age (in years)			0.000	0.962
Male vs Female			-0.032	0.325
Years of Schooling			0.013	0.004
Wealth index			-0.020	0.110
Constant	1.569		1.567	0.000
Threshold 2 (Mild-Moderate)				
Presence of an impairment vs no impairment			0.095	0.344
Rural vs Urban			-0.132	0.065
Age (in years)			-0.003	0.118
Male vs Female			-0.036	0.495
Years of Schooling			-0.008	0.262
Wealth index			0.045	0.025
Constant	2.193		-0.394	0.004
Threshold 3 (Moderate-Severe)				
Presence of an impairment vs no impairment			-0.105	0.393
Rural vs Urban			0.110	0.193
Age (in years)			0.003	0.106
Male vs Female			0.088	0.138
Years of Schooling			0.015	0.059
Wealth index			0.029	0.218
Constant	2.544		-1.222	0.000
Threshold 4 (Severe-Extreme)				
Presence of an impairment vs no impairment			-0.144	0.168
Rural vs Urban			-0.099	0.163
Age (in years)			0.001	0.679

Male vs Female			0.027	0.587
Years of Schooling			-0.019	0.006
Wealth index			-0.030	0.125
Constant	3.287		-0.172	0.202
Vignettes				
θ1			1.344	0.000
θ2			2.213	0.000
θ3			2.329	0.000
θ4			3.399	0.000
θ5			3.537	0.000

Appendix C: Results from Logistic Regression Models

The following tables are the alternative regression tables to the ones that have been presented in the section 7.33 and 7.3.4. The regression tables present results that were obtained from regressing the impairment variable and the functional limitation variable on its own and with the inclusion of the interaction effect.

- Logistic regression output of contraceptive use with interaction effect

Table 7.1 Estimated odds ratios of using contraceptive methods conditional on functional limitation, presence of an impairment and socio-demographic characteristics

Modern contraceptives	Odds Ratio	Standard Error	P-value	[95% Conf. Interval]	
Functional limitation	1.111	0.059	0.054	0.998	1.237
Impairment					
No impairment	Base Outcome				
Has an impairment	0.741	0.440	0.616	0.224	2.454
Age (in years)	1.025	0.009	0.005	1.008	1.043
Wealth index	0.948	0.028	0.075	0.894	1.006
Level of education					
No education	Base Outcome				
Less than Primary	1.560	0.264	0.012	1.108	2.195
Primary completed	1.481	0.305	0.063	0.978	2.243
Secondary and above	1.602	0.563	0.187	0.788	3.255
Place of residence					
Urban	Base Outcome				
Rural	1.183	0.211	0.352	0.825	1.697
Marital Status					
Never married	Base Outcome				
Married or Cohabiting	1.902	0.414	0.005	1.225	2.952
Separated or divorced	1.593	0.543	0.180	0.800	3.171
Widowed	2.319	0.905	0.037	1.055	5.098
Interaction effect					
No impairment & Functional limitation	Base Outcome				
Has an impairment & Functional limitation	0.991	0.289	0.976	0.550	1.785
Constant	0.062	0.024	0.000	0.028	0.136

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- Logistic regression output of contraceptive use with functional limitation only

Table 7.2 Estimated odds ratios of using contraceptive methods conditional on functional limitation and socio-demographic characteristics

Table 7.2 Estimated odds ratios of using contraceptive methods conditional on functional limitation and socio-demographic characteristics					
Modern contraceptives	**Odds Ratio**	**Standard Error**	**P-value**	**[95% Conf. Interval]**	
Functional limitation	1.101	0.060	0.086	0.986	1.230
Age (in years)	1.024	0.009	0.006	1.007	1.042
Wealth index	0.949	0.027	0.076	0.896	1.006
Level of education					
No education	Base outcome				
Less than Primary	1.548	0.260	0.013	1.103	2.171
Primary completed	1.487	0.308	0.062	0.979	2.257
Secondary and above	1.564	0.579	0.234	0.741	3.300
Place of residence					
Urban	Base Outcome				
Rural	1.189	0.219	0.354	0.819	1.725
Marital Status					
Never married	Base Outcome				
Married or Cohabiting	1.931	0.434	0.005	1.227	3.038
Separated or divorced	1.595	0.551	0.184	0.795	3.203
Widowed	2.367	0.937	0.035	1.064	5.264
Constant	0.062	0.024	0.000	0.028	0.136

7.3 Estimated odds ratios of using contraceptive methods conditional on, presence of an impairment and socio-demographic characteristics

Modern contraceptives	Odds Ratio	Standard Error	P-value	[95% Conf. Interval]	
Impairment					
No impairment	Base Outcome				
Has an impairment	0.785	0.362	0.602	0.309	1.993
Age (in years)	1.026	0.009	0.004	1.009	1.044
Wealth index	0.950	0.028	0.090	0.896	1.008
Level of education					
No education	Base Outcome				
Less than Primary	1.574	0.267	0.011	1.118	2.216
Primary completed	1.476	0.305	0.066	0.973	2.239
Secondary and above	1.602	0.555	0.181	0.797	3.222
Place of residence					
Urban	Base Outcome				
Rural	1.175	0.211	0.374	0.818	1.688
Marital Status					
Never married	Base Outcome				
Married or Cohabiting	1.874	0.408	0.006	1.207	2.909
Separated or divorced	1.585	0.536	0.180	0.802	3.135
Widowed	2.284	0.892	0.040	1.038	5.023
Constant	0.061	0.023	0.000	0.028	0.132

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- Logistic regression output of HIV counselling without interaction effect

Table 7.4 Estimated odds ratios of accessing HIV counselling services conditional on functional limitation, presence of an impairment and socio-demographic characteristics

Table 7.4 Estimated odds ratios of accessing HIV counselling services conditional on functional limitation, presence of an impairment and socio-demographic characteristics					
HIV counselling	Odds Ratio	Standard Error	P-value	[95% Conf. Interval]	
Functional limitation	0.593	0.058	0.000	0.486	0.723
Impairment					
No impairment	Base Outcome				
Has an impairment	1.582	1.098	0.512	0.390	6.417
Age (in years)	1.034	0.013	0.009	1.009	1.061
Wealth index	1.007	0.057	0.895	0.899	1.129
Level of education					
No education	Base Outcome				
Less than Primary	1.674	0.390	0.032	1.047	2.678
Primary completed	3.365	1.039	0.000	1.804	6.276
Secondary and above	1.530	0.793	0.416	0.538	4.357
Place of residence					
Urban	Base Outcome				
Rural	0.948	0.241	0.834	0.567	1.585
Marital Status					
Never married	Base Outcome				
Married or Cohabiting	1.969	0.925	0.157	0.763	5.081
Separated or divorced	1.167	0.556	0.747	0.446	3.053
Widowed	2.027	1.160	0.224	0.639	6.431
Constant	0.127	0.087	0.004	0.032	0.506

- Logistic regression output of HIV counselling with functional limitation only

Table 7.5 Estimated odds ratios of accessing HIV counselling services conditional on functional limitation and socio-demographic characteristics

Table 7.5 Estimated odds ratios of accessing HIV counselling services conditional on functional limitation and socio-demographic characteristics					
HIV counselling	**Odds Ratio**	**Standard Error**	**P-value**	**[95% Conf. Interval]**	
Functional limitation	0.598	0.058	0.000	0.492	0.728
Age (in years)	1.034	0.013	0.010	1.008	1.059
Wealth index	1.004	0.057	0.937	0.897	1.125
Level of education					
No education	Base outcome				
Less than Primary	1.671	0.385	0.031	1.050	2.659
Primary completed	3.327	1.002	0.000	1.812	6.109
Secondary and above	1.503	0.760	0.425	0.542	4.172
Place of residence					
Urban	Base Outcome				
Rural	0.951	0.243	0.844	0.567	1.593
Marital Status					
Never married	Base Outcome				
Married or Cohabiting	1.989	0.933	0.150	0.771	5.127
Separated or divorced	1.211	0.575	0.689	0.464	3.159
Widowed	2.036	1.163	0.220	0.643	6.445
Constant	0.130	0.087	0.004	0.034	0.499

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- Logistic regression out of HIV counselling with impairment only

Table 7.6 Estimated odds ratios of accessing HIV counselling services conditional on presence of an impairment and socio-demographic characteristics

Table 7.6 Estimated odds ratios of accessing HIV counselling services conditional on functional limitation, presence of an impairment and socio-demographic characteristics					
Modern contraceptives	**Odds Ratio**	**Standard Error**	**P-value**	**[95% Conf.**	**Interval]**
Impairment					
No impairment	Base Outcome				
Has an impairment	1.063	0.704	0.927	0.279	4.049
Age (in years)	1.025	0.012	0.043	1.001	1.050
Wealth index	0.985	0.056	0.796	0.879	1.105
Level of education					
No education	Base Outcome				
Less than Primary	1.541	0.348	0.063	0.976	2.432
Primary completed	3.275	0.970	0.000	1.801	5.954
Secondary and above	1.484	0.733	0.429	0.548	4.020
Place of residence					
Urban	Base Outcome				
Rural	1.026	0.268	0.923	0.605	1.739
Marital Status					
Never married	Base Outcome				
Married or Cohabiting	1.928	0.919	0.175	0.737	5.044
Separated or divorced	1.155	0.535	0.758	0.453	2.942
Widowed	1.893	1.084	0.272	0.596	6.013
Constant	0.169	0.111	0.010	0.045	0.636

- Logistic regression output of Place of delivery with an interaction effect

Table 7.7 Estimated odds ratios of place of delivery conditional on functional limitation, presence of an impairment and socio-demographic characteristics

Table 7.7 Estimated odds ratios of place of delivery conditional on functional limitation, presence of an impairment and socio-demographic characteristics					
Health facility vs Home	**Odds Ratio**	**Standard Error**	**P-value**	**[95% Conf.**	**Interval]**
Functional limitation	0.940	0.074	0.438	0.802	1.102
Impairment					
No impairment	Base Outcome				
Has an impairment	0.476	0.219	0.113	0.188	1.202
Age (in years)	1.012	0.017	0.465	0.979	1.046
Wealth index	0.859	0.086	0.136	0.703	1.051
Level of education					
No education	Base Outcome				
Less than Primary	1.282	0.215	0.145	0.915	1.797
Primary completed	4.094	1.380	0.000	2.073	8.085
Place of residence					
Urban	Base Outcome				
Rural	0.406	0.100	0.001	0.246	0.669
Marital Status					
Never married	Base Outcome				
Married or Cohabiting	2.730	2.054	0.189	0.598	12.462
Separated or divorced	3.341	2.110	0.063	0.934	11.954
Widowed	7.338	6.905	0.040	1.099	49.011
Interaction effect					
No impairment & Functional limitation	Base Outcome				
Has an impairment & Functional limitation	2.194	1.013	0.096	0.865	5.568
Constant	1.088	0.979	0.926	0.177	6.686

- Logistic regression output of place of delivery with functional limitation only

Table 7.8 Estimated odds ratios of place of delivery conditional on functional limitation and socio-demographic characteristics

Table 7.8 Estimated odds ratios of place of delivery conditional on functional limitation and socio-demographic characteristics					
Health facility vsHome	**Odds Ratio**	**Standard Error**	**P-value**	**[95% Conf. Interval]**	
Functional limitation	0.947	0.075	0.498	0.806	1.112
Age (in years)	1.012	0.016	0.461	0.980	1.046
Wealth index	0.860	0.087	0.145	0.701	1.055
Level of education					
No education	Base outcome				
Less than Primary	1.273	0.214	0.157	0.908	1.786
Primary completed	4.107	1.395	0.000	2.070	8.150
Place of residence					
Urban	Base Outcome				
Rural	0.403	0.099	0.001	0.245	0.663
Marital Status					
Never married	Base Outcome				
Married or Cohabiting	2.680	1.972	0.187	0.607	11.829
Separated or divorced	3.282	2.047	0.064	0.932	11.555
Widowed	7.231	6.611	0.036	1.143	45.759
Constant	1.113	0.964	0.902	0.194	6.391

- Logistic regression output of place of delivery with impairment only

Table 7.9 Estimated odds ratios of place of delivery conditional on presence of an impairment and socio-demographic characteristics

Table 7.9 Estimated odds ratios of place of delivery conditional on presence of an impairment and socio-demographic characteristics					
Health facility vs Home	**Odds Ratio**	**Standard Error**	**P-value**	**[95% Conf. Interval]**	
Impairment					
No impairment	Base Outcome				
Has an impairment	0.778	0.357	0.587	0.308	1.966
Age (in years)	1.011	0.016	0.487	0.979	1.045
Wealth index	0.857	0.088	0.140	0.697	1.054
Level of education					
No education	Base Outcome				
Less than Primary	1.270	0.216	0.168	0.901	1.790
Primary completed	4.110	1.425	0.000	2.042	8.272
Place of residence					
Urban	Base Outcome				
Rural	0.404	0.101	0.001	0.244	0.667
Marital Status					
Never married	Base Outcome				
Married or Cohabiting	2.649	1.962	0.195	0.594	11.810
Separated or divorced	3.277	2.032	0.062	0.938	11.454
Widowed	7.046	6.564	0.042	1.075	46.177
Constant	1.155	1.039	0.873	0.188	7.096

Appendix c

- Multinomial logistic regression output without an interaction effect

Table 7:10 Estimated Relative Risks of being assisted by a health professional during child-birth by functional limitation, presence of an impairment and socio-demographic characteristics

	Table 7:11 Estimated Relative Risks of being assisted by a health professional during child-birth by functional limitation, presence of an impairment and socio-demographic characteristics				
Assistance during delivery	**Relative Risk Ratio**	**Standard Error**	**P-value**	**[95% Conf. Interval]**	
Doctor/Nurse/Midwife	(Base Outcome)				
Traditional Birth Attendant					
Functional limitation	1.258	0.200	0.157	0.912	1.734
Impairment					
No impairment	Base Outcome				
Has an impairment	1.095	0.687	0.886	0.309	3.884
Age (in years)	0.988	0.018	0.527	0.952	1.026
Wealth index	1.070	0.128	0.572	0.841	1.363
Level of education					
No education	Base Outcome				
Less than Primary	0.691	0.183	0.171	0.404	1.181
Primary completed	0.219	0.084	0.000	0.101	0.475
Secondary and above	0.116	0.121	0.045	0.014	0.949
Place of residence					
Urban	Base Outcome				
Rural	1.653	0.699	0.242	0.704	3.880
Constant	0.580	0.394	0.427	0.147	2.286
Relative or Friend					
Functional limitation	1.107	0.123	0.365	0.885	1.385
Impairment					
No impairment	Base Outcome				
Has an impairment	0.999	0.682	0.999	0.252	3.962
Age (in years)	0.988	0.019	0.518	0.950	1.027
Wealth index	1.149	0.112	0.160	0.944	1.398
Level of education					
No education	Base Outcome				
Less than Primary	0.579	0.122	0.013	0.379	0.884
Primary completed	0.292	0.101	0.001	0.145	0.587
Secondary and above	0.085	0.101	0.045	0.008	0.941
Place of residence					
Urban	Base Outcome				
Rural	2.395	0.905	0.026	1.117	5.133
Constant	0.269	0.224	0.122	0.050	1.442

- Multinomial logistic regression output with functional limitation only

Table 7.11 Estimated Relative Risks of being assisted by a health professional during child-birth by functional limitation, presence of an impairment and socio-demographic characteristics

Table 7.12 Estimated Relative Risks of being assisted by a health professional during child-birth by functional limitation, presence of an impairment and socio-demographic characteristics					
Doctor/Nurse/Midwife	**Relative Risk Ratio**	**Standard Error**	**P-value**	**[95% Conf. Interval]**	
Traditional Birth Attendant					
Functional limitation	1.26	0.20	0.154	0.91	1.74
Age (in years)	0.99	0.02	0.524	0.95	1.03
Wealth index	1.07	0.13	0.573	0.84	1.36
Level of education					
No education	Base Outcome				
Less than Primary	0.69	0.18	0.171	0.40	1.18
Primary completed	0.22	0.08	0.000	0.10	0.47
Secondary and above	0.12	0.12	0.044	0.01	0.94
Place of residence					
Urban	Base Outcome				
Rural	1.65	0.70	0.241	0.70	3.88
Constant	0.58	0.40	0.431	0.15	2.29
Relative or Friend					
Functional limitation	1.11	0.12	0.345	0.89	1.37
Age (in years)	0.99	0.02	0.511	0.95	1.03
Wealth index	1.15	0.11	0.161	0.94	1.40
Level of education					
No education	Base Outcome				
Less than Primary	0.58	0.12	0.013	0.38	0.88
Primary completed	0.29	0.10	0.001	0.15	0.59
Secondary and above	0.09	0.10	0.045	0.01	0.95
Place of residence					
Urban	Base Outcome				
Rural	2.39	0.90	0.026	1.12	5.13
Constant	0.27	0.22	0.115	0.05	1.39

- Multinomial logistic regression with impairment measure only

Table 7.12 Estimated Relative Risks of being assisted by a health professional during child-birth by presence of an impairment and socio-demographic characteristics

Doctor/Nurse/Midwife	*Relative Risk Ratio*	*Standard Error*	*P-value*	*[95% Conf. Interval]*	
Traditional Birth Attendant					
Impairment					
No impairment	Base Outcome				
Has an impairment	1.284	0.785	0.684	0.374	4.410
Age (in years)	0.991	0.019	0.649	0.953	1.031
Wealth index	1.082	0.131	0.516	0.848	1.381
Level of education					
No education	Base Outcome				
Less than Primary	0.708	0.197	0.221	0.404	1.241
Primary completed	0.220	0.086	0.000	0.100	0.482
Secondary and above	0.117	0.125	0.051	0.014	1.012
Place of residence					
Urban	Base Outcome				
Rural	1.605	0.642	0.243	0.716	3.598
Constant	0.540	0.386	0.394	0.128	2.283
Relative or Friend					
Impairment					
No impairment	Base Outcome				
Has an impairment	1.073	0.697	0.914	0.290	3.977
Age (in years)	0.989	0.019	0.571	0.951	1.028
Wealth index	1.155	0.113	0.150	0.947	1.407
Level of education					
No education	Base Outcome				
Less than Primary	0.586	0.124	0.015	0.383	0.898
Primary completed	0.293	0.102	0.001	0.145	0.590
Secondary and above	0.086	0.102	0.045	0.008	0.947
Place of residence					
Urban	Base Outcome				
Rural	2.362	0.907	0.030	1.089	5.125
Constant	0.259	0.215	0.111	0.048	1.384

Table 7.13 Estimated Relative Risks of being assisted by a health professional during child-birth by functional limitation, presence of an impairment and socio-demographic characteristics					
Doctor/Nurse/Midwife	**Relative Risk Ratio**	**Standard Error**	**P-value**	**[95% Conf. Interval]**	
Traditional Birth Attendant					
Impairment					
No impairment	Base Outcome				
Has an impairment	1.284	0.785	0.684	0.374	4.410
Age (in years)	0.991	0.019	0.649	0.953	1.031
Wealth index	1.082	0.131	0.516	0.848	1.381
Level of education					
No education	Base Outcome				
Less than Primary	0.708	0.197	0.221	0.404	1.241
Primary completed	0.220	0.086	0.000	0.100	0.482
Secondary and above	0.117	0.125	0.051	0.014	1.012
Place of residence					
Urban	Base Outcome				
Rural	1.605	0.642	0.243	0.716	3.598
Constant	0.540	0.386	0.394	0.128	2.283
Relative or Friend					
Impairment					
No impairment	Base Outcome				
Has an impairment	1.073	0.697	0.914	0.290	3.977
Age (in years)	0.989	0.019	0.571	0.951	1.028
Wealth index	1.155	0.113	0.150	0.947	1.407
Level of education					
No education	Base Outcome				
Less than Primary	0.586	0.124	0.015	0.383	0.898
Primary completed	0.293	0.102	0.001	0.145	0.590
Secondary and above	0.086	0.102	0.045	0.008	0.947
Place of residence					
Urban	Base Outcome				
Rural	2.362	0.907	0.030	1.089	5.125
Constant	0.259	0.215	0.111	0.048	1.384

Appendix D: Quantitative Survey Instruments

Appendix D1: 2003 Malawi World Health Survey- Individual questionnaire

2000. Health State Descriptions

Time Begin: __ __ : __ __

Overall Health

The first questions are about your overall health, including both your physical and your mental health.

Q2000	In general, how would you rate your health today?	1. Very good	2. Good	3. Moderate	4. Bad	5. Very Bad
Q2001	Overall in the last 30 days, how much difficulty did you have with work or household activities?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do

Now I would like to review 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 an average, in the past 30 days, while doing the activity in the way that you usually do it. By difficulty I mean requiring increased effort, discomfort or pain, slowness or changes in the way you do the activity. Please answer this question taking into account any assistance you have available. (**Read and show scale to respondent**).

Mobility

Q2010	Overall in the last 30 days, how much difficulty did you have with moving around?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do
Q2011	In the last 30 days, how much difficulty did you have in vigorous activities, such as running 3 km (or equivalent) or cycling?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do

Self Care

Q2020	Overall in the last 30 days, how much difficulty did you have with self-care, such as washing or dressing yourself?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do
Q2021	In the last 30 days, how much difficulty did you have in taking care of and maintaining your general appearance (e.g. grooming, looking neat and tidy etc.)	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do

Pain and Discomfort

Q2030	Overall in the last 30 days, how much of bodily aches or pains did you have?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme
Q2031	In the last 30 days, how much bodily discomfort did you have?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme

Cognition

Q2050	Overall in the last 30 days, how much difficulty did you have with concentrating or remembering things?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do

| Q2051 | In the last 30 days, how much difficulty 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 etc.)? | 1. None | 2. Mild | 3. Moderate | 4. Severe | 5. Extreme/ Cannot do |

Interpersonal Activities

| Q2060 | Overall in the last 30 days, how much difficulty did you have with personal relationship or participation in the community? | 1. None | 2. Mild | 3. Moderate | 4. Severe | 5. Extreme/ Cannot do |
| Q2061 | In the last 30 days, how much difficulty did you have in dealing with conflicts and tensions with others? | 1. None | 2. Mild | 3. Moderate | 4. Severe | 5. Extreme/ Cannot do |

Vision

Q2070	Do you wear glasses or contact lenses? (If Respondent says YES to this question, preface the next 2 questions with "Please answer the following questions taking into account your glasses or contact lenses".)	1. Yes		5. No		
Q2071	In the last 30 days, how much difficulty did you have in seeing and recognizing a person you know across the road (i.e. from a distance of about 20 meters)?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do
Q2072	In the last 30 days, how much difficulty did you have in seeing and recognizing an object at arm's length or in reading?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do

Sleep and Energy

| Q2080 | Overall 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? | 1. None | 2. Mild | 3. Moderate | 4. Severe | 5. Extreme |
| Q2081 | In the last 30 days, how much of a problem did you have due to not feeling rested and refreshed during the day (e.g. feeling tired, not having energy)? | 1. None | 2. Mild | 3. Moderate | 4. Severe | 5. Extreme |

Affect

| Q2090 | Overall in the last 30 days, how much of a problem did you have with feeling sad, low or depressed? | 1. None | 2. Mild | 3. Moderate | 4. Severe | 5. Extreme |
| Q2091 | Overall in the last 30 days, how much of a problem did you have with worry or anxiety? | 1. None | 2. Mild | 3. Moderate | 4. Severe | 5. Extreme |

Appendix D2: 2003 Malawi World Health Survey-anchoring vignettes

VIGNETTES FOR HEALTH STATE DESCRIPTIONS: Set-A

Mobility and Affect

[Jan] feels nervous and anxious. He worries and thinks negatively about the future, but feels better in the company of people or when doing something that really interests him. When he is alone he tends to feel useless and empty.

Q2101	Overall in the last 30 days, how much of a problem did [name of person] have with feeling sad, low, or depressed?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme
Q2102	In the last 30 days, how much of a problem did [name of person] have with worry or anxiety?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme

[Mary] has no problems with walking, running or using her hands, arms and legs. She jogs 4 kilometres twice a week.

Q2103	Overall in the last 30 days, how much of a problem did [name of person] have with moving around?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do
Q2104	In the last 30 days, how much difficulty did [name of person] have in vigorous activities, such as running 3 km (or equivalent) or cycling?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do

[Anton] does not exercise. He cannot climb stairs or do other physical activities because he is obese. He is able to carry the groceries and do some light household work.

Q2105	Overall in the last 30 days, how much of a problem did [name of person] have with moving around?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do
Q2106	In the last 30 days, how much difficulty did [name of person] have in vigorous activities, such as running 3 km (or equivalent) or cycling?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do

[David] is paralyzed from the neck down. He is unable to move his arms and legs or to shift body position. He is confined to bed.

Q2107	Overall in the last 30 days, how much difficulty did [name of person] have with moving around?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do
Q2108	In the last 30 days, how much difficulty did [name of person] have in vigorous activities, such as running 3 km (or equivalent) or cycling?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do

[Ken] loves life and is happy all the time. He never worries or gets upset about anything and deals with things as they come.

Q2109	Overall in the last 30 days, how much of a problem did [name of person] have with feeling sad, low, or depressed?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme

| Q2110 | In the last 30 days, how much of a problem did [name of person] have with worry or anxiety? | 1. None | 2. Mild | 3. Moderate | 4. Severe | 5. Extreme |

[Rob] is able to walk distances of up to 200 metres without any problems but feels tired after walking one kilometre or climbing up more than one flight of stairs. He has no problems with day-to-day physical activities, such as carrying food from the market

| Q2111 | Overall in the last 30 days, how much difficulty did [name of person] have with moving around? | 1. None | 2. Mild | 3. Moderate | 4. Severe | 5. Extreme/ Cannot do |
| Q2112 | In the last 30 days, how much difficulty did [name of person] have in vigorous activities, such as running 3 km (or equivalent) or cycling? | 1. None | 2. Mild | 3. Moderate | 4. Severe | 5. Extreme/ Cannot do |

[Vincent] has a lot of swelling in his legs due to his health condition. He has to make an effort to walk around his home as his legs feel heavy.

| Q2113 | Overall in the last 30 days, how much of a problem did [name of person] have with moving around? | 1. None | 2. Mild | 3. Moderate | 4. Severe | 5. Extreme/ Cannot do |
| Q2114 | In the last 30 days, how much difficulty did [name of person] have in vigorous activities, such as running 3 km (or equivalent) or cycling? | 1. None | 2. Mild | 3. Moderate | 4. Severe | 5. Extreme/ Cannot do |

[Vivian] has already had five admissions into the hospital because she has attempted suicide twice in the past year and has harmed herself on three other occasions. She is very distressed every day for the most part of the day, and sees no hope of things ever getting better. She is thinking of trying to end her life again.

| Q2115 | Overall in the last 30 days, how much of a problem did [name of person] have with feeling sad, low, or depressed? | 1. None | 2. Mild | 3. Moderate | 4. Severe | 5. Extreme |
| Q2116 | In the last 30 days, how much of a problem did [name of person] have with worry or anxiety? | 1. None | 2. Mild | 3. Moderate | 4. Severe | 5. Extreme |

[Roberta] feels depressed most of the time. She weeps frequently and feels hopeless about the future. She feels that she has become a burden on others and that she would be better dead.

| Q2117 | Overall in the last 30 days, how much of a problem did [name of person] have with feeling sad, low, or depressed? | 1. None | 2. Mild | 3. Moderate | 4. Severe | 5. Extreme |
| Q2118 | In the last 30 days, how much of a problem did [name of person] have with worry or anxiety? | 1. None | 2. Mild | 3. Moderate | 4. Severe | 5. Extreme |

[Henriette] enjoys her work and social activities and is generally satisfied with her life. She gets depressed every 3 weeks for a day or two and loses interest in what she usually enjoys but is able to carry on with her day to day activities.

| Q2119 | Overall in the last 30 days, how much of a problem did [name of person] have with feeling sad, low, or depressed? | 1. None | 2. Mild | 3. Moderate | 4. Severe | 5. Extreme |

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| Q2120 | Overall in the last 30 days, how much of a problem did [name of person] have with distress, sadness or worry? | 1. None | 2. Mild | 3. Moderate | 4. Severe | 5. Extreme |

VIGNETTES FOR HEALTH STATE DESCRIPTIONS: Set-B

Pain and Personal Relationships

[Mark] has pain in his knees, elbows, wrists and fingers, and the pain is present almost all the time. It gets worse during the first half of the day. Although medication helps, he feels uncomfortable when moving around, holding and lifting things.

Q2101	Overall in the last 30 days, how much of <u>bodily aches or pains</u> did [name of person] have?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme
Q2102	In the last 30 days, how much <u>bodily discomfort</u> did [name of person] have?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme

[Elizabeth] has difficulty climbing up and down the stairs and walking. She is not able to go out as much as she would like to but has many friends who come and visit her at home. Her friends find her a source of great comfort.

Q2103	Overall in the last 30 days, how much difficulty did [name of person] have with <u>personal relationships or participation in the community</u>?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do
Q2104	In the last 30 days, how much difficulty did [name of person] have in <u>dealing with conflicts and tensions</u> with others?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do

[Amala] suffered a stroke three months ago. Her friends do not come and visit anymore as Amala cannot communicate with them. She is constantly upset and shouts at her family members which causes them to avoid her.

Q2105	Overall in the last 30 days, how much difficulty did [name of person] have with <u>personal relationship or participation in the community</u>?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do
Q2106	In the last 30 days, how much difficulty did [name of person] have in <u>dealing with conflicts and tensions</u> with others?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do

[Katie] cannot remember when she last felt pain as this has not happened for the last several years now. She does not experience any pain even after hard physical labor or exercise.

Q2107	Overall in the last 30 days, how much of <u>bodily aches or pains</u> did [name of person] have?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme
Q2108	In the last 30 days, how much <u>bodily discomfort</u> did [name of person] have?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme

[Charlie] can join in any community activities that interest him, whenever he wants to, without any restrictions. He gets on well with everybody and enjoys meeting new people.

Q2109	Overall in the last 30 days, how much difficulty did [name of person] have with <u>personal relationship or participation in the community</u>?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do
Q2110	In the last 30 days, how much difficulty did [name of person] have in <u>dealing with conflicts and tensions</u> with others?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do

[Steve] has pain in the neck radiating to the arms that is not relieved by any medicines or other treatment. The pain is sharp at all times and keeps him awake most of the night. During the day the pain has made him completely incapacitated. It has necessitated complete confinement to the bed and often makes him think of ending his life.

Q2111	Overall in the last 30 days, how much of <u>bodily aches or pains</u> did [name of person] have?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme
Q2112	In the last 30 days, how much bodily discomfort did [name of person] have?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme

[Johanna] gets on well with the people she knows but has no close friends. She has not spoken to her mother in 5 years and does not want to see her. Because of this tension, her family usually excludes her from family gatherings.

Q2113	Overall in the last 30 days, how much difficulty did [name of person] have with <u>personal relationship or participation in the community</u>?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do
Q2114	In the last 30 days, how much difficulty did [name of person] have in <u>dealing with conflicts and tensions</u> with others?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do

[Laura] has a headache once a month that is relieved one hour after taking a pill. During the headache she can carry on with her day to day affairs.

Q2115	Overall in the last 30 days, how much of <u>bodily aches or pains</u> did [name of person] have?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme
Q2116	In the last 30 days, how much <u>bodily discomfort</u> did [name of person] have?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme

[Nobu] is blind and lives in a remote rural area. His family does not allow him to leave the house because they fear he will get hurt. His family tells him that he is a burden to them. Their criticism upsets him and he cries.

Q2117	Overall in the last 30 days, how much difficulty did [name of person] have with <u>personal relationships or participation in the community</u>?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do

Q2118	In the last 30 days, how much difficulty did [name of person] have in <u>dealing with conflicts and tensions</u> with others?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do

[Isabelle] has pain that radiates down her right arm and wrist during her day at work. This is slightly relieved in the evenings when she is no longer working on her computer.

Q2119	Overall in the last 30 days, how much of <u>bodily aches or pains</u> did [name of person] have?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do
Q2120	In the last 30 days, how much bodily discomfort did [name of person] have?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme

VIGNETTES FOR HEALTH STATE DESCRIPTIONS: Set-C

Vision, Sleep and Energy

[Jennifer] only reads if the text is in very large print, such as 10 lines per page. Otherwise she does not read anything. Even when people are close to her, she sees them blurred.

Q2101	In the last 30 days, how much difficulty did you think [name of person] have in <u>seeing and recognizing a person she knows across the road</u> (i.e. from a distance of about 20 meters)?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do
Q2102	In the last 30 days, how much difficulty did you think [name of person] have in <u>seeing and recognizing an object at arm's length or in reading</u>?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do

[Paolo] has no trouble falling asleep at night and does not wake up during the night, but every morning he finds it difficult to wake up. He uses an alarm clock but falls back asleep after the alarm goes off. He is late to work on four out of five days and feels tired in the mornings.

Q2103	In the last 30 days, how much difficulty do you think [name of person] had with sleeping, such as <u>falling asleep</u>, <u>waking up frequently during the night</u> or <u>waking up too early</u> in the morning?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme
Q2104	In the last 30 days, how much of a problem did you have due to not <u>feeling rested and refreshed</u> during the day (e.g. feeling tired, not having energy)?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme

[Hector] can read words in newspaper articles (and can recognize faces on a postcard size photograph). He can recognize familiar people's faces all the time and picks out most details in pictures from across 20 metres.

Q2105	In the last 30 days, how much difficulty did you think [name of person] have in <u>seeing and recognizing a person she knows across the road</u> (i.e. from a distance of about 20 meters)?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do
Q2106	In the last 30 days, how much difficulty did you think [name of person] have in <u>seeing and recognizing an object at arm's length or in reading</u>?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme

[Damien] wakes up almost once every hour during the night. When she wakes up in the night, it takes around 15 minutes for her to go back to sleep. In the morning she does not feel well-rested and feels slow and tired all day.

Q2107	In the last 30 days, how much difficulty do you think [name of person] had with sleeping, such as <u>falling asleep</u>, <u>waking up frequently during the night</u> or <u>waking up too early</u> in the morning?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme

Q2108	In the last 30 days, how much of a problem did you have due to not <u>feeling rested and refreshed</u> during the day (e.g. feeling tired, not having energy)?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme

[Daniel] takes about two hours every night to fall asleep. He wakes up once or twice a night feeling panicked and takes more than one hour to fall asleep again. Three to four nights a week he wakes up in the middle of the night and cannot go back to sleep for the rest of the night. He is fatigued all day, every day and misses work several times a week. He cannot take part in sports or social activities.

Q2109	In the last 30 days, how much difficulty do you think [name of person] had with sleeping, such as <u>falling asleep</u>, <u>waking up frequently during the night</u> or <u>waking up too early</u> in the morning?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme
Q2110	In the last 30 days, how much of a problem did you have due to not <u>feeling rested and refreshed</u> during the day (e.g. feeling tired, not having energy)?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme

[Norman] needs a magnifying glass to read small print and look at details on pictures. He also takes a while to recognize objects if they are too far from him.

Q2111	In the last 30 days, how much difficulty did you think [name of person] have in <u>seeing and recognizing a person she knows across the road</u> (i.e. from a distance of about 20 meters)?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do
Q2112	In the last 30 days, how much difficulty did you think [name of person] have in <u>seeing and recognizing an object at arm's length or in reading</u>?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do

[Antonio] can read words in newspaper articles (and can recognize faces on a postcard size photograph). He can recognize shapes and colours from across 20 metres but misses out the fine details.

Q2113	In the last 30 days, how much difficulty did you think [name of person] have in <u>seeing and recognizing a person she knows across the road</u> (i.e. from a distance of about 20 meters)?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do
Q2114	In the last 30 days, how much difficulty did you think [name of person] have in <u>seeing and recognizing an object at arm's length or in reading</u>?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do

[Noemi] falls asleep easily at night, but two nights a week she wakes up in the middle of the night and cannot go back to sleep for the rest of the night. On these days she is exhausted at work and cannot concentrate on her job.

Q2115	In the last 30 days, how much difficulty do you think [name of person] had with sleeping, such as <u>falling asleep</u>, <u>waking up frequently during the night</u> or <u>waking up too early in the morning</u>?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme
Q2116	In the last 30 days, how much of a problem did you have due to not <u>feeling rested and refreshed</u> during the day (e.g. feeling tired, not having energy)?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme

[Sebastian] cannot detect any movement close to the eyes or even the presence of a light.

Q2117	In the last 30 days, how much difficulty did you think [name of person] have in <u>seeing and recognizing a person she knows across the road</u> (i.e. from a distance of about 20 meters)?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do
Q2118	In the last 30 days, how much difficulty did you think [name of person] have in <u>seeing and recognizing an object at arm's length or in reading</u>?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do

[Mark] falls asleep every night within five minutes of going to bed. He sleeps soundly during the whole night and wakes up in the morning feeling well-rested and feels full of energy all day.

Q2119	In the last 30 days, how much difficulty do you think [name of person] had with sleeping, such as <u>falling asleep</u>, <u>waking up frequently during the night or waking up too early in the morning</u>?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme
Q2120	In the last 30 days, how much of a problem did you have due to not <u>feeling rested and refreshed</u> during the day (e.g. feeling tired, not having energy)?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme

VIGNETTES FOR HEALTH STATE DESCRIPTIONS: **Set-D**

Cognition and Self Care

[Helena] pays a lot of attention to the way she looks. She requires no assistance with cleanliness, dressing and eating.

Q2101	Overall in the last 30 days, how much difficulty did [name of person] have with <u>self-care</u>, such as washing or dressing himself/herself?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do
Q2102	In the last 30 days, how much difficulty did [name of person] have in <u>taking care of and maintaining his/her general appearance</u> (e.g. grooming, looking neat and tidy etc.)	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do

[Sue] can find her way around the neighborhood and know where her own belongings are kept, but struggles to remember how to get to a place she has only visited once or twice. She is keen to learn new recipes but finds that she often makes mistakes and has to reread several times before she is able to do them properly.

Q2103	Overall in the last 30 days overall how much difficulty did [name of the person] have with <u>concentrating or remembering things</u>?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do
Q2104	In the last 30 days, how much difficulty did [name of person] have in <u>learning a new task</u> (for example, learning how to get to a new place, learning a new game, learning a new recipe etc.)?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do

[Sue] is quadriplegic and must be washed, groomed, dressed and fed by somebody else.

Q2105	Overall in the last 30 days, how much difficulty did [name of person] have with <u>self-care</u>, such as washing or dressing himself/herself?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do
Q2106	In the last 30 days, how much difficulty did [name of person] have in <u>taking care of and maintaining his/her general appearance</u>(e.g. grooming, looking neat and tidy etc.)	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do

[Malcolm] can concentrate while watching TV, reading a magazine or playing a game of cards or chess. He can learn new variations in these games with small effort. Once a week he forgets where his keys or glasses are, but finds them within five minutes.

Q2107	Overall in the last 30 days overall how much difficulty did [name of the person] have with <u>concentrating or remembering things</u>?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do
Q2108	In the last 30 days, how much difficulty did [name of person] have in <u>learning a new task</u> (for example, learning how to get to a new place, learning a new game, learning a new recipe etc.)?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do

[Rob] is very quick to learn new skills at his work. He can pay attention to the task at hand for long uninterrupted periods of time. He can remember names of people, addresses, phone numbers and such details that go back several years.

Q2109	Overall in the last 30 days overall how much difficulty did [name of the person] have with <u>concentrating or remembering things</u>?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do
Q2110	In the last 30 days, how much difficulty did [name of person] have in <u>learning a new task</u> (for example, learning how to get to a new place, learning a new game, learning a new recipe etc.)?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do

[Theo] cannot concentrate for more than 15 minutes and has difficulty paying attention to what is being said to him. Whenever he starts a task, he never manages to finish it and often forgets what he was doing. He is able to learn the names of people he meets but cannot be trusted to follow directions to a store by himself.

Q2111	Overall in the last 30 days overall how much difficulty did [name of the person] have with <u>concentrating or remembering things</u>?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do
Q2112	In the last 30 days, how much difficulty did [name of person] have in <u>learning a new task</u> (for example, learning how to get to a new place, learning a new game, learning a new recipe etc.)?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do

[Anne] takes twice as long as others to put on and take off clothes, but needs no help with this. Although it requires an effort, she is able to bathe and groom herself, though less frequently than before. She does not require help with feeding.

Q2113	Overall in the last 30 days, how much difficulty did [name of person] have with <u>self-care</u>, such as washing or dressing himself/herself?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do
Q2114	In the last 30 days, how much difficulty did [name of person] have in <u>taking care of and maintaining his/her general appearance</u>(e.g. grooming, looking neat and tidy etc.)	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme

[Peter] does not recognize even close relatives and gets lost when he leaves the house unaccompanied. Even when prompted, he shows no recollection of events or recognition of relatives. It is impossible for him to acquire any new knowledge as even simple instructions leave him confused.

Q2115	Overall in the last 30 days overall how much difficulty did [name of the person] have with <u>concentrating or remembering things</u>?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do
Q2116	In the last 30 days, how much difficulty did [name of person] have in <u>learning a new task</u> (for example, learning how to get to a new place, learning a new game, learning a new recipe etc.)?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do

[Sandra] lives on her own and has no relatives or friends nearby. Because of her arthritis, she is house-bound. She often stays all day in the same clothes that she has slept in, as changing clothes is too painful. A neighbour helps her wash herself.

Q2117	Overall in the last 30 days, how much difficulty did [name of person] have with <u>self-care</u>, such as washing or dressing himself/herself?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do
Q2118	In the last 30 days, how much difficulty did [name of person] have in <u>taking care of and maintaining his/her general appearance</u> (e.g. grooming, looking neat and tidy etc.)	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do

[Victor] requires no assistance with cleanliness, dressing and eating. He occasionally suffers from back pain and when this happens he needs help with bathing and dressing. He always keeps himself tidy.

Q2119	Overall in the last 30 days, how much difficulty did [name of person] have with <u>self-care</u>, such as washing or dressing himself/herself?	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do
Q2120	In the last 30 days, how much difficulty did [name of person] have in <u>taking care of and maintaining his/her general appearance</u> (e.g. grooming, looking neat and tidy etc.)	1. None	2. Mild	3. Moderate	4. Severe	5. Extreme/ Cannot do

List of References

Abdul Karimu, A.T.F. (2018) 'Disabled persons in Ghanaian health strategies: reflections on the 2016 adolescent reproductive health policy', *Reproductive health matters*, 26(54), pp. 20-24.

Abimanyi-Ochom, J. *et al.* (2017) 'HIV/AIDS knowledge, attitudes and behaviour of persons with and without disabilities from the Uganda Demographic and Health Survey 2011: Differential access to HIV/AIDS information and services', *Plos one*, 12(4), p. e0174877.

Aboderin, I.A. and Beard, J.R. (2015) 'Older people's health in sub-Saharan Africa', *The Lancet*, 385(9968), pp. e9-e11.

ACFA (2017) 'The sexual and reproductive health services and rights' *Survey report blief*. Kampala Uganda: ACFA Uganda.

Adebayo, B. (2018) 'Hunted for their body parts and stigmatized: Malawi's albinos will contents elections', *CNN*. Available at: https://edition.cnn.com/2018/06/26/africa/albino-contest-malawi-election/index.html.

African Union (2006) 'Maputo Plan of Action for the operationalization of the continental policy frame work for Sexual and Reproductive Health and Rights; 2007-2010', *Maputo: African Union Commission*.

Agbenyega, J. (2003) *A paper presented at the Australian Association for Research in Education Conference, Newcastle, Association of Active Educational Researchers (AARE)*. Citeseer.

Agresti A (2007) *An Introduction to Categorical Data Analysis*. 3rd Edition edn. New York: Wiley.

Ahumuza, S.E. *et al.* (2014) 'Challenges in accessing sexual and reproductive health services by people with physical disabilities in Kampala, Uganda', *Reproductive health*, 11(1), p. 59.

Al-Aoufi, H., Al-Zyoud, N. and Shahminan, N. (2012) 'Islam and the cultural conceptualisation of disability', *International Journal of Adolescence and Youth*, 17(4), pp. 205-219.

Aljazoli, A. (2004) 'Islam position on disability', *Morocco: ISESCO*.

Altman, B.M. (2001) 'Disability definitions, models, classification schemes, and applications', *Handbook of disability studies*, pp. 97-122.

Alycia Reppel, M., Segun Dawodu, MD (2014) 'CONCEPTUAL MODELS OF DISABILITY', *PM&R Knowledge*.

Amin, M. *et al.* (2011) 'EquiFrame: A framework for analysis of the inclusion of human rights and vulnerable groups in health policies', *Health Hum Rights*, 13(2), pp. 1-20.

Amnesty International (2016) *Albinism in Malawi: Stop the killings*. Available at: https://www.amnesty.org/en/latest/campaigns/2016/06/albinism-in-malawi-stop-the-killings/ (Accessed: 08 April 2018).

The ritual murders of people with albinism in Malawi (2017).

Angwenyi, V. *et al.* (2018) 'Patients experiences of self-management and strategies for dealing with chronic conditions in rural Malawi', *PloS one*, 13(7), p. e0199977.

List of References

Arcella, S. *et al.* (2009) 'A situational analysis of the sexual and reproductive health of women with disabilities'. New York: United Nations Publications.

Au, N. and Lorgelly, P.K. (2014) 'Anchoring vignettes for health comparisons: an analysis of response consistency', *Quality of Life Research*, 23(6), pp. 1721-1731.

Austin, P.C. (2011) 'An introduction to propensity score methods for reducing the effects of confounding in observational studies', *Multivariate behavioral research*, 46(3), pp. 399-424.

Ayiga, N. and Kigozi, S. (2016) 'Access to and Uptake of Contraception by Women with Disabilities', *Population Research and Training Unit. Journal of Social Science*.

Azevedo, L.O.d., Queiroz, R.S.B. and Rezende, C.E.M.d. (2005) 'The World Health Survey: a report on the field experience in Brazil', *Cadernos de saude publica*, 21, pp. S25-S32.

Baker, C. *et al.* (2010) 'The myths surrounding people with albinism in South Africa and Zimbabwe', *Journal of African Cultural Studies*, 22(2), pp. 169-181.

Baker, F.B. and Kim, S.-H. (2017) *The Basics of Item Response Theory Using R*. Springer.

Barbour, R. (2000) 'The role of qualitative research in broadening the 'evidence base'for clinical practice', *Journal of evaluation in clinical practice*, 6(2), pp. 155-163.

Barke, A., Nyarko, S. and Klecha, D. (2011) 'The stigma of mental illness in Southern Ghana: attitudes of the urban population and patients' views', *Social psychiatry and psychiatric epidemiology*, 46(11), pp. 1191-1202.

Barriga, S.R. and Kwon, S.-R. (2010) *" As If We Weren't Human": Discrimination and Violence Against Women with Disabilities in Northern Uganda*. Human Rights Watch.

Basu, A.M. and Stephenson, R. (2005) 'Low levels of maternal education and the proximate determinants of childhood mortality: a little learning is not a dangerous thing', *Social science & medicine*, 60(9), pp. 2011-2023.

Baxter C. and Mahoney W. (2018) *Developmental disability across cultues*. Available at: https://www.kidsnewtocanada.ca/mental-health/developmental-disability (Accessed: 23 July 2019).

Becker, H., Stuifbergen, A. and Tinkle, M. (1997) 'Reproductive health care experiences of women with physical disabilities: a qualitative study', *Archives of physical medicine and rehabilitation*, 78(12), pp. S26-S33.

Bell, E., and Corby, N., (2019,) *HIV prevention, treatment and care programming for people with*

disabilities, Disability Inclusion Helpdesk Research Report No. 7. London, UK:: Inclusion, D. and Helpdes.

Bicego, G., Boerma, J.T. and Ronsmans, C. (2002) 'The effect of AIDS on maternal mortality in Malawi and Zimbabwe', *Aids*, 16(7), pp. 1078-1081.

Biel Portero, I. and Bolaños Enríquez, T.G. (2018) 'Persons with disabilities and the Colombian armed conflict', *Disability & Society*, 33(3), pp. 487-491.

Bijl, R.V. and Ravelli, A. (2000) 'Current and residual functional disability associated with psychopathology: findings from the Netherlands Mental Health Survey and Incidence Study (NEMESIS)', *Psychological medicine*, 30(3), pp. 657-668.

Bora, J.K. and Saikia, N. (2015) 'Gender differentials in self-rated health and self-reported disability among adults in India', *PloS one*, 10(11), p. e0141953.

Bowie, C. (2006) 'The burden of disease in Malawi', *Malawi Medical Journal*, 18(3), pp. 104-110.

Boyce, C. and Neale, P. (2006) 'Conducting in-depth interviews: A guide for designing and conducting in-depth interviews for evaluation input'.

Braathen, S.H. and Ingstad, B. (2006) 'Albinism in Malawi: knowledge and beliefs from an African setting', *Disability & Society*, 21(6), pp. 599-611.

Braun, V. and Clarke, V. (2006) 'Using thematic analysis in psychology', *Qualitative research in psychology*, 3(2), pp. 77-101.

Brazier, J., Deverill, M. and Green, C. (1999) 'A review of the use of health status measures in economic evaluation', *Journal of health services research & policy*, 4(3), pp. 174-184.

Breidt, F.J. and Opsomer, J.D. (2000) 'Local polynomial regression estimators in survey sampling', *Annals of Statistics*, pp. 1026-1053.

Bremer, K., Cockburn, L. and Ruth, A. (2010) 'Reproductive health experiences among women with physical disabilities in the Northwest Region of Cameroon', *International Journal of Gynecology & Obstetrics*, 108(3), pp. 211-213.

Brocco, G. (2015) 'Labeling albinism: language and discourse surrounding people with albinism in Tanzania', *Disability & Society*, 30(8), pp. 1143-1157.

Browning, C.R. and Cagney, K.A. (2002) 'Neighborhood structural disadvantage, collective efficacy, and self-rated physical health in an urban setting', *Journal of health and social behavior*, pp. 383-399.

Bryman, A. (2016) *Social research methods*. Oxford university press.

Bunning, K. *et al.* (2017) 'The perception of disability by community groups: Stories of local understanding, beliefs and challenges in a rural part of Kenya', *PloS one*, 12(8), p. e0182214.

Bwalya, R. *et al.* (2017) 'Bridging the Gap Secondary Data Analysis'.

Caldwell, J.C. and Caldwell, P. (1987) 'The cultural context of high fertility in sub-Saharan Africa', *Population and development review*, pp. 409-437.

Cappa, C., Petrowski, N. and Njelesani, J. (2015) 'Navigating the landscape of child disability measurement: A review of available data collection instruments', *ALTER-European Journal of Disability Research/Revue Européenne de Recherche sur le Handicap*, 9(4), pp. 317-330.

Carr, A.J., Gibson, B. and Robinson, P.G. (2001) 'Is quality of life determined by expectations or experience?', *Bmj*, 322(7296), pp. 1240-1243.

Chakraborty, N. *et al.* (2003) 'Determinants of the use of maternal health services in rural Bangladesh', *Health promotion international*, 18(4), pp. 327-337.

Chamie, M. (1989) 'The status and use of the International Classification of Impairments, Disabilities and Handicaps (ICIDH)', *World health statistics quarterly. Rapport trimestriel de statistiques sanitaires mondiales*, 43(4), pp. 273-280.

Chang, K.-H. *et al.* (2015) 'Association between muscle power impairment and WHODAS 2.0 in older adults with physical disability in Taiwan', *Disability and rehabilitation*, 37(8), pp. 712-720.

List of References

Cheng, S.-T., Fung, H. and Chan, A. (2007) 'Maintaining self-rated health through social comparison in old age', *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 62(5), pp. P277-P285.

Chung, I.M. (1998) 'Dispelling the Myths about Addiction', *Drug and Alcohol Review*, 17(3), p. 331.

Cleland, J.G. and Van Ginneken, J.K. (1988) 'Maternal education and child survival in developing countries: the search for pathways of influence', *Social science & medicine*, 27(12), pp. 1357-1368.

Coleridge, P. (2000) 'Disability and culture', *Selected Readings in Community Based Rehabilitation Series*, 1, pp. 21-38.

Cortina, J.M. (1993) 'What is coefficient alpha? An examination of theory and applications', *Journal of applied psychology*, 78(1), p. 98.

Crabb, J. *et al.* (2012) 'Attitudes towards mental illness in Malawi: a cross-sectional survey', *BMC Public Health*, 12(1), p. 541.

Creswell, J.W. and Creswell, J.D. (2017) *Research design: Qualitative, quantitative, and mixed methods approaches*. Sage publications.

Creswell, J.W. and Inquiry, Q. (2007) 'Research design: choosing among five approaches'. Sage, Thousand Oaks, California.

Cruz-Inigo, A.E., Ladizinski, B. and Sethi, A. (2011) 'Albinism in Africa: stigma, slaughter and awareness campaigns', *Dermatologic clinics*, 29(1), pp. 79-87.

Curtis, K.A. *et al.* (1999) 'Shoulder pain in wheelchair users with tetraplegia and paraplegia', *Archives of physical medicine and rehabilitation*, 80(4), pp. 453-457.

D'Orazio, M., Di Zio, M. and Scanu, M. (2006) *Statistical matching: Theory and practice*. John Wiley & Sons.

D'silva, M.U. *et al.* (2016) 'Reflexivity and Positionality in Researching African-American Communities: Lessons from the Field', *Intercultural Communication Studies*, 25(1).

D'Orazio, M. (2011) 'Statistical Matching and Imputation of Survey Data with the Package StatMatch for the R Environment', *R package vignette http://www. cros-portal. eu/sites/default/files//Statistical_Matching_with_StatMatch. pdf*.

D'Orazio, M. (2016) 'Statistical Matching and Imputation of Survey Data with StatMatch'.

D'Orazio, M., Di Zio, M. and Scanu, M. (2010) 'Old and new approaches in statistical matching when samples are drawn with complex survey designs', *Proceedings of the 45th "Riunione Scientifica della Societa'Italiana di Statistica", Padova*, pp. 16-18.

D'Orazio, M., Di Zio, M. and Scanu, M. (2012) *Proceedings of the European Conference on Quality in Official Statistics-Q2012*.

Damacena, G.N., Vasconcellos, M.T.L.d. and Szwarcwald, C.L. (2005) 'Perception of health state and the use of vignettes to calibrate for socioeconomic status: results of the World Health Survey in Brazil, 2003', *Cadernos de Saúde Pública*, 21, pp. S65-S77.

De Beaudrap, P., Mac-Seing, M. and Pasquier, E. (2014) 'Disability and HIV: a systematic review and a meta-analysis of the risk of HIV infection among adults with disabilities in Sub-Saharan Africa', *AIDS care*, 26(12), pp. 1467-1476.

De Beaudrap, P. *et al.* (2016) 'HandiVIH—A population-based survey to understand the vulnerability of people with disabilities to HIV and other sexual and reproductive health problems in Cameroon: protocol and methodological considerations', *BMJ open*, 6(2), p. e008934.

de Kok, B. (2008) 'Infertility in Malawi: Exploring its impact and social consequences'.

de Lepper, M., Scholten, H.J. and Stern, R.M. (1995) *The Added Value of Geographical Information Systems in Public and Environmental Health: Kluwer*. Springer Science & Business Media.

de Waal, T. (2015) 'Statistical matching: Experimental results and future research questions'.

Deaton, A.S. and Tortora, R. (2015) 'People in Sub-Saharan Africa rate their health and health care among the lowest in the world', *Health Affairs*, 34(3), pp. 519-527.

DeBeaudrap, P. *et al.* (2019) 'Disability and Access to Sexual and Reproductive Health Services in Cameroon: A Mediation Analysis of the Role of Socioeconomic Factors', *International journal of environmental research and public health*, 16(3), p. 417.

Degener, T. (2014) 'A human rights model of disability', *Disability Social Rights*.

Deviant, S. (2011) *The practically cheating statistics handbook*. Lulu. com.

Deville, J.-C. and Särndal, C.-E. (1992) 'Calibration estimators in survey sampling', *Journal of the American statistical Association*, 87(418), pp. 376-382.

Di Giulio, G. (2003) 'Sexuality and People Living with Physical or Developmental Disabilities: A Review of Key Issues', *Canadian Journal of Human Sexuality*, 12(1).

Donatiello, G. *et al.* (2014) 'Statistical matching of income and consumption expenditures', *International Journal of Economic Sciences*, 3(3), pp. 50-65.

DOrazio, M. (2013) 'Statistical matching: Metodological issues and practice with R-StatMtach'.

Dowd, J.B. and Todd, M. (2011) 'Does self-reported health bias the measurement of health inequalities in US adults? Evidence using anchoring vignettes from the Health and Retirement Study', *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 66(4), pp. 478-489.

Dowd, J.B. and Zajacova, A. (2007) 'Does the predictive power of self-rated health for subsequent mortality risk vary by socioeconomic status in the US?', *International Journal of Epidemiology*, 36(6), pp. 1214-1221.

Dulani, B. (2003) 'How participatory is participation in social funds? An analysis of three case studies from the Malawi Social Action Fund,(MASAF)', *Development*, 23.

Durkin, M. (2001) *International Seminar on Measurement of Disability, New York*.

Dwyer, S.C. and Buckle, J.L. (2009) 'The space between: On being an insider-outsider in qualitative research', *International journal of qualitative methods*, 8(1), pp. 54-63.

Edhlund, B. and McDougall, A. (2017) *Nvivo 11 essentials*. Lulu. com.

Edmonds, W.A. and Kennedy, T.D. (2012) *An Applied Reference Guide to Research Designs: Quantitative, Qualitative, and Mixed Methods: Quantitative, Qualitative, and Mixed Methods*. Sage.

Eide, A.H. and Munthali, A. (2018) *Living conditions among persons with disabilities in Malawi*.

List of References

Faresjö, T. and Faresjö, Å. (2010) 'To match or not to match in epidemiological studies—same outcome but less power', *International journal of environmental research and public health*, 7(1), pp. 325-332.

FEDOMA (2006) *Effective HIV/AIDS and Reproductive Health Information for Persons with Disbailities: A right's Based Approach*. Malawi: FEDOMA. Available at: http://www.fedomamalawi.org/public/themes/Fedoma/downloads/FEDOMA-CIDA-GESP-FINAL-REPORT.pdf.

Feyisetan Bamikale et al (2014) *Evaluation of Youth-Freindly Health Services in Malawi,* . Washington, USA: The Evidence to Action Project (E2A). Available at: https://www.e2aproject.org/wp-content/uploads/evaluation-yfhs-malawi.pdf.

Field, A. (2013) *Discovering statistics using IBM SPSS statistics*. Sage.

Fisher, T. (2008) 'Assessing function in the elderly: Katz ADL and Lawton IADL', *Dalhousie University. Measuring Health Outcomes*.

Fried, L.P. *et al.* (2000) 'Preclinical mobility disability predicts incident mobility disability in older women', *Journals of Gerontology-Biological Sciences and Medical Sciences*, 55(1), p. M43.

Friedmann, J.M., Elasy, T. and Jensen, G.L. (2001) 'The Relationship Between Body Mass Index and Self-Reported Functional Limitation Among Older Adults: A Gender Difference', *Journal of the American Geriatrics Society*, 49(4), pp. 398-403.

Fritz, J.M. and Piva, S.R. (2003) 'Physical impairment index: reliability, validity, and responsiveness in patients with acute low back pain', *Spine*, 28(11), pp. 1189-1194.

Froberg, D.G. and Kane, R.L. (1989) 'Methodology for measuring health-state preferences—III: population and context effects', *Journal of Clinical Epidemiology*, 42(6), pp. 585-592.

Ganga, D. and Scott, S. (2006) *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research*.

Ganle, J.K. *et al.* (2016) 'Challenges women with disability face in accessing and using maternal healthcare services in Ghana: A qualitative study', *PloS one*, 11(6), p. e0158361.

Gill, C.J. (1987) 'A new social perspective on disability and its implications for rehabilitation', *Occupational therapy in health care*, 4(1), pp. 49-55.

Glasier, A. *et al.* (2006) 'Sexual and reproductive health: a matter of life and death', *The Lancet*, 368(9547), pp. 1595-1607.

Goforth, C. (2015) 'Using and interpreting Cronbach's Alpha', *Statistical Consulting Associate, University of Virginia Library*.

Griffin, S. (2006) 'Literature review on sexual and reproductive health rights: universal access to services, focussing on East and Southern Africa and South Asia', *Panos, London: Department for International Development*.

Groce et al (2009) 'Promoting the sexual and reproductive health of people with disability'.

Groce, N. (1999) 'Framing Disability Issues in Local Concepts and Beliefs', *Asia Pacific Disability Rehabilitation Journal*, 10(1), pp. 4-7.

Groce, N. (2006) 'Cultural beliefs and practices that influence the type and nature of data collected on individuals with disability through national census', in *International views on*

disability measures: moving toward comparative measurement. Emerald Group Publishing Limited, pp. 41-54.

Groce, N. and Bakhshi, P. (2009) 'Illiteracy among adults with disabilities in the developing world: An unexplored area of concern'.

Groce, N. *et al.* (2011) 'Disability and poverty: The need for a more nuanced understanding of implications for development policy and practice', *Third World Quarterly*, 32(8), pp. 1493-1513.

Groce, N.E. (2004) 'Adolescents and youth with disability: issues and challenges', *Asia Pacific Disability Rehabilitation Journal*, 15(2), pp. 13-32.

Groce, N.E. and Mont, D. (2017) 'Counting disability: emerging consensus on the Washington Group questionnaire', *The Lancet Global Health*, 5(7), pp. e649-e650.

Grol-Prokopczyk, H., Freese, J. and Hauser, R.M. (2011) 'Using anchoring vignettes to assess group differences in general self-rated health', *Journal of health and social behavior*, 52(2), pp. 246-261.

Grol-Prokopczyk, H. *et al.* (2015) 'Promises and pitfalls of anchoring vignettes in health survey research', *Demography*, 52(5), pp. 1703-1728.

Grönvik, L. (2007) 'Definitions of disability in social sciences: Methodological perspectives'.

Grundy, E. and Holt, G. (2000) 'Adult life experiences and health in early old age in Great Britain', *Social science & medicine*, 51(7), pp. 1061-1074.

Guion, L.A., Diehl, D.C. and McDonald, D. (2001) *Conducting an in-depth interview*. University of Florida Cooperative Extension Service, Institute of Food and Agricultural Sciences, EDIS.

Gureje, O. *et al.* (2005) 'Community study of knowledge of and attitude to mental illness in Nigeria', *The British Journal of Psychiatry*, 186(5), pp. 436-441.

Guzman-Castillo, M. *et al.* (2017) 'Forecasted trends in disability and life expectancy in England and Wales up to 2025: a modelling study', *The Lancet Public Health*, 2(7), pp. e307-e313.

Habtamu, K. *et al.* (2017) 'Validation of the World Health Organization Disability Assessment Schedule in people with severe mental disorders in rural Ethiopia', *Health and quality of life outcomes*, 15(1), p. 64.

Hanass-Hancock, J., Strode, A. and Grant, C. (2011) 'Inclusion of disability within national strategic responses to HIV and AIDS in Eastern and Southern Africa', *Disability and Rehabilitation*, 33(22-23), pp. 2389-2396.

Hanga, K., DiNitto, D. and Leppik, L. (2016) 'Initial assessment of rehabilitation needs using the WHODAS 2.0 in Estonia', *Disability and rehabilitation*, 38(3), pp. 260-267.

Harrell, F. (2015) *Regression modeling strategies: with applications to linear models, logistic and ordinal regression, and survival analysis*. Springer.

Henderson, R.H. and Sundaresan, T. (1982) 'Cluster sampling to assess immunization coverage: a review of experience with a simplified sampling method', *Bulletin of the World Health Organization*, 60(2), p. 253.

Hendricks, A. (2007) 'UN Convention on the Rights of Persons with Disabilities', *Eur. J. Health L.*, 14, p. 273.

List of References

Hermann, K.M. and Reese, C.S. (2001) 'Relationships among selected measures of impairment, functional limitation, and disability in patients with cervical spine disorders', *Physical therapy*, 81(3), pp. 903-912.

Hirve, S. *et al.* (2013) 'Use of anchoring vignettes to evaluate health reporting behavior amongst adults aged 50 years and above in Africa and Asia–testing assumptions', *Global health action*, 6(1), p. 21064.

Holmes, A. (2014) 'Researcher positionality–a consideration of its influence and place in research', *University of Hull*.

Holzer, B., Vreede, A. and Weigt, G. (1999) *Disability in different cultures: Reflections on local concepts*. Transcript.

Hopkins, D.J. and King, G. (2010) 'Improving anchoring vignettes designing surveys to correct interpersonal incomparability', *Public opinion quarterly*, 74(2), pp. 201-222.

Hosmer Jr, D.W., Lemeshow, S. and Sturdivant, R.X. (2013) *Applied logistic regression*. John Wiley & Sons.

Hosseinpoor, A.R. *et al.* (2016) 'Socio-demographic patterns of disability among older adult populations of low-income and middle-income countries: results from World Health Survey', *International journal of public health*, 61(3), pp. 337-345.

Hughes, R. and Huby, M. (2002) 'The application of vignettes in social and nursing research', *Journal of advanced nursing*, 37(4), pp. 382-386.

Hyman, S.E. (2000) 'The genetics of mental illness: implications for practice', *Bulletin of the World Health Organization*, 78, pp. 455-463.

Idler, E.L. and Benyamini, Y. (1997) 'Self-rated health and mortality: a review of twenty-seven community studies', *Journal of health and social behavior*, pp. 21-37.

Iezzoni, L.I. *et al.* (2014) 'Conditions causing disability and current pregnancy among US women with chronic physical disabilities', *Medical care*, 52(1), p. 20.

Ingstad, B. (1995) *Disability and culture*. Univ of California Press.

Ivanova, O., Dræbel, T. and Tellier, S. (2015) 'Are sexual and reproductive health policies designed for all? Vulnerable groups in policy documents of four European countries and their involvement in policy development', *International journal of health policy and management*, 4(10), p. 663.

Jaccard, J. (2001) 'Interaction effects in logistic regression (Vol. 135)', *NY: Sage*.

Jafar, A.J. (2018) 'What is positionality and should it be expressed in quantitative studies?'. BMJ Publishing Group Ltd and the British Association for Accident ….

Jejeebhoy, S.J. (1995) 'Women's education, autonomy, and reproductive behaviour: Experience from developing countries', *OUP Catalogue*.

Jette, A.M. (2006) 'Toward a common language for function, disability, and health', *Physical therapy*, 86(5), p. 726.

Johnson, R.B. and Onwuegbuzie, A.J. (2004) 'Mixed methods research: A research paradigm whose time has come', *Educational researcher*, 33(7), pp. 14-26.

Jylhä, M. (2009) 'What is self-rated health and why does it predict mortality? Towards a unified conceptual model', *Social science & medicine*, 69(3), pp. 307-316.

Jylhä, M. *et al.* (2001) 'Walking Difficulty, Walking Speed, and Age as Predictors of Self-Rated Health The Women's Health and Aging Study', *The Journals of gerontology Series A: Biological Sciences and Medical Sciences*, 56(10), pp. M609-M617.

Kanjo, C. (2011) 'Pragmatism or policy: Implications on health information systems success', *The Electronic Journal of Information Systems in Developing Countries*, 48(1), pp. 1-20.

Kassa, T.A. *et al.* (2016) 'Sexual and reproductive health of young people with disability in Ethiopia: a study on knowledge, attitude and practice: a cross-sectional study', *Globalization and health*, 12(1), p. 5.

Katsui, H. (2008) *Downside of the human rights-based approach to disability in development*. Helsinki university. Institute of development studies.

Kauye, F. *et al.* (2011) 'Increasing the capacity of health surveillance assistants in community mental health care in a developing country, Malawi', *Malawi Medical Journal*, 23(3), pp. 85-88.

Kendall, J. and Anglewicz, P. (2016) 'Living arrangements and health at older ages in rural Malawi', *Ageing & Society*, pp. 1-23.

Khasnabis, C. *et al.* (2010) *Community-based rehabilitation: CBR guidelines*. World Health Organization.

King, G. *et al.* (2004) 'Enhancing the validity and cross-cultural comparability of measurement in survey research', *American political science review*, 98(01), pp. 191-207.

King, G. and Nielsen, R. (2016) 'Why propensity scores should not be used for matching', *Copy at http://j. mp/1sexgVw Download Citation BibTex Tagged XML Download Paper*, 378.

King, G. and Wand, J. (2007) 'Comparing incomparable survey responses: Evaluating and selecting anchoring vignettes', *Political Analysis*, 15(1), pp. 46-66.

Kishindo, P. (2000) 'Community project funding in Malawi under the Malawi Social Action Fund (MASAF) demand-driven approach: potential for perpetuating imbalances in development'.

Kitzinger, J. (1995) 'Qualitative research. Introducing focus groups', *BMJ: British medical journal*, 311(7000), p. 299.

Kok, M.C. *et al.* (2016) 'Health surveillance assistants as intermediates between the community and health sector in Malawi: exploring how relationships influence performance', *BMC health services research*, 16(1), p. 164.

Konecky, B. *et al.* (2014) 'Using the WHODAS 2.0 to assess functional disability associated with DSM-5 mental disorders', *American Journal of Psychiatry*, 171(8), pp. 818-820.

Kostanjsek, N. (2011) 'Use of The International Classification of Functioning, Disability and Health (ICF) as a conceptual framework and common language for disability statistics and health information systems', *BMC Public Health*, 11(Suppl 4), p. S3.

Kott, P. (2012) 'An Introduction to Calibration Weighting for Establishment Survey', *Survey Methodology*, pp. 8-10.

Kulnik, S.T. and Nikoletou, D. (2014) 'WHODAS 2.0 in community rehabilitation: A qualitative investigation into the validity of a generic patient-reported measure of disability', *Disability and rehabilitation*, 36(2), pp. 146-154.

Kululanga, L.I., Sundby, J. and Chirwa, E. (2012) 'Male involvement in maternity health care in Malawi', *African journal of reproductive health*, 16(1), pp. 145-157.

List of References

Kumbani, L. *et al.* (2013) 'Why some women fail to give birth at health facilities: a qualitative study of women's perceptions of perinatal care from rural Southern Malawi', *Reproductive health*, 10(1), p. 9.

Kwadwo, W., Anafi, P. and Sekyere, F.O. (2014) 'Does disability matter? Disability in sexual and reproductive health policies and research in Ghana', *International quarterly of community health education*, 35(1), pp. 21-35.

Lafortune, G. and Balestat, G. (2007) 'Trends in severe disability among elderly people'.

Larsson, U.E. and Mattsson, E. (2001) 'Perceived disability and observed functional limitations in obese women', *International journal of obesity*, 25(11), p. 1705.

Latham, N.K. *et al.* (2008) 'Performance-based or self-report measures of physical function: which should be used in clinical trials of hip fracture patients?', *Archives of physical medicine and rehabilitation*, 89(11), pp. 2146-2155.

Lee, K. *et al.* (2015) 'Sexual and reproductive health services for women with disability: a qualitative study with service providers in the Philippines', *BMC women's health*, 15(1), p. 87.

Leidy, N.K. (1994) 'Functional status and the forward progress of merry-go-rounds: toward a coherent analytical framework', *Nursing research*, 43(4), pp. 196-202.

Leonardi, M. *et al.* (2005) 'The global burden of migraine: measuring disability in headache disorders with WHO's Classification of Functioning, Disability and Health (ICF)', *The journal of headache and pain*, 6(6), p. 429.

Leshner, A.I. (1997) 'Addiction is a brain disease, and it matters', *Science*, 278(5335), pp. 45-47.

Leslie, H.H. *et al.* (2016) 'Obstetric facility quality and newborn mortality in Malawi: a cross-sectional study', *PLoS medicine*, 13(10), p. e1002151.

Leulescu, A. and Agafitei, M. (2013) 'Statistical matching: a model based approach for data integration', *Eurostat-Methodologies and Working papers*.

Link, B.G. *et al.* (1999) 'Public conceptions of mental illness: labels, causes, dangerousness, and social distance', *American journal of public health*, 89(9), pp. 1328-1333.

Link, B.G. *et al.* (2004) 'Measuring mental illness stigma', *Schizophrenia bulletin*, 30(3), p. 511.

Liu, H. and Hummer, R.A. (2008) 'Are educational differences in US self-rated health increasing?: An examination by gender and race', *Social Science & Medicine*, 67(11), pp. 1898-1906.

Loeb, M. (2016) 'International census/survey data and the short set of disability questions developed by the Washington group on disability statistics', in *International Measurement of Disability*. Springer, pp. 255-304.

Loeb, M.E. and Eide, A.H. (2004) 'Living Conditions among People with Activity Limitations in Malawi: A National Representative Study'.

Loeb, M.E., Eide, A.H. and Mont, D. (2008) 'Approaching the measurement of disability prevalence: the case of Zambia', *ALTER-European Journal of Disability Research/Revue Européenne de Recherche sur le Handicap*, 2(1), pp. 32-43.

Lohela, T.J., Campbell, O.M. and Gabrysch, S. (2012) 'Distance to care, facility delivery and early neonatal mortality in Malawi and Zambia', *PLoS One*, 7(12), p. e52110.

Long-Bellil, L. *et al.* (2017) 'The impact of physical disability on pregnancy and childbirth', *Journal of Women's Health*, 26(8), pp. 878-885.

Lynch, P., Lund, P. and Massah, B. (2014) 'Identifying strategies to enhance the educational inclusion of visually impaired children with albinism in Malawi', *International Journal of Educational Development*, 39, pp. 216-224.

Mack, N. *et al.* (2005) 'Qualitative research methods: a data collectors field guide'.

MacLachlan, M. *et al.* (2012) 'Inclusion and human rights in health policies: Comparative and benchmarking analysis of 51 policies from Malawi, Sudan, South Africa and Namibia', *PLoS One*, 7(5), p. e35864.

Maclachlan, M., Nyirenda, T. and Nyando, C. (1995) 'Attributions for admission to Zomba Mental Hospital: implications for the development of mental health services in Malawi', *International Journal of Social Psychiatry*, 41(2), pp. 79-87.

Mactaggart, I. *et al.* (2016) 'Measuring disability in population based surveys: the interrelationship between clinical impairments and reported functional limitations in Cameroon and India', *PloS one*, 11(10), p. e0164470.

Madans, J.H., Loeb, M.E. and Altman, B.M. (2011) 'Measuring disability and monitoring the UN Convention on the Rights of Persons with Disabilities: the work of the Washington Group on Disability Statistics', *BMC public health*, 11(4), p. 1.

Madow, W.G. (1949) 'On the theory of systematic sampling, II', *The Annals of Mathematical Statistics*, pp. 333-354.

Malawi Government (1971) *Handiccaped Persons Act*. Malawi: Malawi Government.

Malawi Government (2006) *National Policy on Equalization of Opportunities for persons with Disabilities,*. Lilongwe: Malawi Government.

Malawi Government (2007) *Zomba District Socio-Economic Profile*. Lilongwe, Malawi: Malawi Government. Available at: https://www.yumpu.com/en/document/view/51290400/zomba-socio-economic-profile-2007draft-scotland-malawi-.

Malawi Government (2010) *Blantyre District Socio-Economic Profile*. Blantyre: Blantyre District Assembly. Available at: https://www.yumpu.com/en/document/view/34833884/blantyre-socio-economic-profile-2007-2010draft-scotland-malawi-.

Malawi Government (2011) *National HIV and AIDS policy*. Lilongwe, Malawi: Office of the President and Cabinet. Available at: http://populationmalawi.org/wp1/wp-content/uploads/2013/09/NATIONAL-HIV-AND-AIDS-POLICY-Final-No-tracks_April-13.pdf.

Malawi Government (2012) *National Sexual and Reproductive Health and Rights Strategy (2011-2016)*. Lilongwe, Malawi: Ministry of Health Available at: http://www.mamaye.org/en/evidence/malawi-national-reproductive-health-strategy-2006-2010-0.

Malawi Government (2015) *National Youth Freindly Health Services Strategy, 2015-2020*. Lilongwe, Malawi: Malawi Government. Available at: https://www.healthpolicyproject.com/pubs/673_YFHSStrategyFINALWEB.pdf.

Malawi Government (2016) *National Cervical Cancer Control Strategy 2016-2020*. Lilongwe, Malawi: Ministry of Health. Available at: http://malawi.unfpa.org/sites/default/files/resource-pdf/National_Cervical_Cancer_Strategy_A5_30Oct17_WEB.pdf.

List of References

Malawi Government (2017) *Health Sector Strategic Plan II 2017-2022*. Lilongwe, Malawi: Ministry of Health.

Malawi National statistics office (2001) *Malawi Demographic and health survey 2000*. Zomba: National statistics Office.

Mannan, H. *et al.* (2011) 'The EquiFrame Manual', *Dublin: The EquitAble Consortium*.

Manor, O., Matthews, S. and Power, C. (2000) 'Dichotomous or categorical response? Analysing self-rated health and lifetime social class', *International Journal of Epidemiology*, 29(1), pp. 149-157.

Marcello, D., Di Zio, M. and Scanu, M. (2006) 'Statistical matching for categorical data: Displaying uncertainty and using logical constraints', *Journal of Official Statistics*, 22(1), p. 137.

Marija, J. (2003) *SPSS 12.0 Statistical Procedures Companion*. Prentice Hall.

Marx, B.P. *et al.* (2015) 'Using the WHODAS 2.0 to assess functioning among veterans seeking compensation for posttraumatic stress disorder', *Psychiatric Services*, 66(12), pp. 1312-1317.

Masala, C. and Petretto, D.R. (2008) 'From disablement to enablement: conceptual models of disability in the 20th century', *Disability and Rehabilitation*, 30(17), pp. 1233-1244.

Mavuso, S.S. and Maharaj, P. (2015) 'Access to sexual and reproductive health services: Experiences and perspectives of persons with disabilities in Durban, South Africa', *Agenda*, 29(2), pp. 79-88.

Mbogoni, M. (2003) 'On the application of the ICIDH and ICF in developing countries: evidence from the United Nations Disability Statistics Database (DISTAT)', *Disability and rehabilitation*, 25(11-12), pp. 644-658.

McDowell, I. (2006) *Measuring health: a guide to rating scales and questionnaires*. Oxford university press.

McHugh, M.L. (2013) 'The chi-square test of independence', *Biochemia medica: Biochemia medica*, 23(2), pp. 143-149.

Merrill, S.S. *et al.* (1997) 'Gender differences in the comparison of self-reported disability and performance measures', *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 52(1), pp. M19-M26.

Meyer, C. *et al.* (2016) *Seminars in hearing*. Thieme Medical Publishers.

Miilunpalo, S. *et al.* (1997) 'Self-rated health status as a health measure: the predictive value of self-reported health status on the use of physician services and on mortality in the working-age population', *Journal of clinical epidemiology*, 50(5), pp. 517-528.

Ministry of Health (2009) *National Sexual and reproductive Health and Rights (SRHR) Policy*. Lilongwe, Malawi: Malawi Government, . Available at: http://malawi.unfpa.org/sites/default/files/pub-pdf/SRHR%20POLICY%20FINAL.pdf.

Ministry of Health (2012) *Malawi Nationa Health Policy*. Lilongwe, Malawi: Malawi Government.

Ministry of Health (2017) *2017-2022 National Sexual and Reproductive Health and Rights (SRHR) policy*. Malawi: Government of Malawi. Available at: http://malawi.unfpa.org/sites/default/files/resource-pdf/Malawi_National_SRHR_Policy_2017-2022_16Nov17.pdf.

Ministry of Health and Population (2002) *Reproductive Health Policy* Lilongwe: Malawi Government Available at: http://www.postabortioncare.org/sites/pac/files/MOHMal_RH_Policy.pdf.

Mitra, S. (2006) 'The capability approach and disability', *Journal of disability policy studies*, 16(4), pp. 236-247.

Mitra, S., Posarac, A. and Vick, B. (2013) 'Disability and poverty in developing countries: a multidimensional study', *World Development*, 41, pp. 1-18.

Mitra, S. and Sambamoorthi, U. (2014) 'Disability prevalence among adults: estimates for 54 countries and progress toward a global estimate', *Disability and rehabilitation*, 36(11), pp. 940-947.

Mji et al , G.S., Wazakili Margaret and Skinner Donald, (2008) 'The Call on HIV/AIDS and Reproductive Health Care amongst Disabled People in Malawi and Namibia'. Capetown, South Africa: Stellenbosch University and Universityof Western Cape. Available at: https://assets.publishing.service.gov.uk/media/57a08bc4ed915d3cfd000f18/HIVandAIDS.pdf.

Mont, D. (2007a) 'Measuring disability prevalence', *World Bank Social Protection Discussion Paper*, 706.

Mont, D. (2007b) 'Measuring health and disability', *The Lancet*, 369(9573), p. 1658.

Moriarity, C. and Scheuren, F. (2001) 'Statistical matching: a paradigm for assessing the uncertainty in the procedure', *Journal of Official Statistics*, 17(3), p. 407.

Morris, A. (2015) *A practical introduction to in-depth interviewing*. Sage.

Morrison, J. *et al.* (2014) 'Disabled women' s maternal and newborn health care in rural Nepal: A qualitative study', *Midwifery*, 30(11), pp. 1132-1139.

Morrow, M. *et al.* (2007) 'Fostering disability-inclusive HIV/AIDS programs in northeast India: a participatory study', *BMC Public Health*, 7(1), p. 125.

Mosher, W. *et al.* (2018) 'Contraceptive use by disability status: new national estimates from the National Survey of Family Growth', *Contraception*, 97(6), pp. 552-558.

Mosselson, J. (2010) 'Subjectivity and reflexivity: Locating the self in research on dislocation', *International Journal of Qualitative Studies in Education*, 23(4), pp. 479-494.

Moyo, D.S. (2010) 'Ensuring sexual and reproductive health rights of women with disabilities: A study of policies, actions and commitments in Uganda and Zimbabwe'.

Mprah, W.K. (2013) 'Knowledge and use of contraceptive methods amongst deaf people in Ghana', *African Journal of Disability*, 2(1), p. 9 pages.

Munthali, A. *et al.* (2014) 'Non-use of formal health services in Malawi: perceptions from non-users', *Malawi Medical Journal*, 26(4), pp. 126-132.

Munthali, A., Mvula, P. and Ali, S. (2004) 'Effective HIV/AIDS and reproductive health information to people with disabilities'.

Munthali, A.C. (2011) 'A Situation Analysis of Persons with Disabilities in Malawi'.

Munthali, A.C. *et al.* (2017) '"This one will delay us": barriers to accessing health care services among persons with disabilities in Malawi', *Disability and rehabilitation*, pp. 1-8.

List of References

Murray, C. and Lopez, A.D. (1996) 'Summary: The global burden of disease: A comprehensive assessment of mortality and disability from diseases, injuries, and risk factors in 1990 and projected to 2020', *Geneva and Boston: World Health Organization and Harvard School of Public Health*.

Murray, C.J. *et al.* (2002) 'Armed conflict as a public health problem', *Bmj*, 324(7333), pp. 346-349.

Murtagh, K.N. and Hubert, H.B. (2004) 'Gender differences in physical disability among an elderly cohort', *American journal of public health*, 94(8), pp. 1406-1411.

Murthy, G.V.S., John, N. and Sagar, J. (2014) 'Reproductive health of women with and without disabilities in South India, the SIDE study (South India Disability Evidence) study: a case control study', *BMC women's health*, 14(1), p. 146.

Murthy, M.N. (1967) 'Sampling theory and methods', *Sampling theory and methods.*

Nelson, F. *et al.* (2017) 'The meaning of participation for children in Malawi: insights from children and caregivers', *Child: care, health and development*, 43(1), pp. 133-143.

Newsom, J.T. *et al.* (2003) 'Investigating moderator hypotheses in aging research: Statistical, methodological, and conceptual difficulties with comparing separate regressions', *The International Journal of Aging and Human Development*, 57(2), pp. 119-150.

Njelesani, J. *et al.* (2012) 'Using a human rights-based approach to disability in disaster management initiatives', in *Natural Disasters*. InTech.

Nosek, M.A. *et al.* (2001) 'National study of women with physical disabilities: Final report', *Sexuality and disability*, 19(1), pp. 5-40.

Nosek, M.A., Wuermser, L.-A. and Walter, L.J. (1998) 'Differences in contraceptive methods used by women with physical disabilities compared to women without disabilities', *Primary care update for Ob/Gyns*, 5(4), pp. 172-173.

Nosek, M.A. *et al.* (1995) 'Barriers to reproductive health maintenance among women with physical disabilities', *Journal of Women's Health*, 4(5), pp. 505-518.

Nowell, L.S. *et al.* (2017) 'Thematic analysis: Striving to meet the trustworthiness criteria', *International Journal of Qualitative Methods*, 16(1), p. 1609406917733847.

NSO (2005) *Malawi Demographic and Health Survey 2004*. Zomba, Malawi: Malawi Government.

NSO (2008) *Population and Housing Census* Zomba, Malawi.

NSO (2009) *Welfare monitoring survey*. Zomba, Malawi: Malawi National statistics office. Available at: http://www.nsomalawi.mw/images/stories/data_on_line/agriculture/wms_2009/WMS%202009 %20%20%20%2015th%20%20JULY%202010.pdf.

NSO (2010a) *Population and Housing Census: Analytical report on Disability and the Elderly*. National Statistics Office.

NSO (2010b) *Population Projections in Malawi*. Zomba: Malawi National statistics Office. Available at: http://www.nsomalawi.mw/images/stories/data_on_line/demography/census_2008/Main%20Re port/ThematicReports/Population%20Projections%20Malawi.pdf.

NSO (2011) *Malawi Demographic and Health Survey 2010*. Zomba, Malawi.

NSO (2012) *Intergrated Household Survey 2010-2011*. Zomba: Malawi government. Available at: http://www.nsomalawi.mw/images/stories/data_on_line/economics/ihs/IHS3/IHS3_Report.pdf.

NSO (2016a) *Malawi Demographic and Health Survey 2015-16*. Zomba: Malawi National statistical Office. Available at: http://www.nsomalawi.mw/images/stories/data_on_line/demography/mdhs2015_16/Malawi%20DHS%202015-16%20KIR.pdf.

NSO (2016b) *Malawi Demographic and Health Survey 2015-16, Key indicators report*. Zomba, Malawi: National statistical Office. Available at: http://www.nsomalawi.mw/images/stories/data_on_line/demography/mdhs2015_16/Malawi%20DHS%202015-16%20KIR.pdf.

NSO (2017) *Integrated Household Survey 2016-2017*. Zomba: Malawi Government. Available at: http://www.nsomalawi.mw/images/stories/data_on_line/economics/ihs/IHS4/IHS4%20REPORT.pdf.

O'Connell, A.A. (2006) *Logistic regression models for ordinal response variables*. Sage. 146.

O'Day, B. and Killeen, M. (2002) 'Research on the lives of persons with disabilities: The emerging importance of qualitative research methodologies', *Journal of Disability Policy Studies*, 13(1), pp. 9-15.

Oliver, M. (1996) *Understanding disability: From theory to practice*. St Martin's Press.

Oliver, M. (2004) 'If I had a hammer: The social model in action', *Disabling barriers–Enabling environments*, 2, pp. 7-12.

Ostini, R. and Nering, M.L. (2006) *Polytomous item response theory models*. Sage. 144.

Overseas Development Institute (2009) *Research tools: Focus group discussion*. Available at: https://www.odi.org/publications/5695-focus-group-discussion (Accessed: 04/04/2018).

Palmer, M. and Harley, D. (2012) 'Models and measurement in disability: an international review', *Health Policy and Planning*, 27(5), pp. 357-364.

Park, M. and Fuller, W.A. (2012) 'Generalized regression estimators', *Encyclopedia of Environmetrics*.

Peikes, D.N., Moreno, L. and Orzol, S.M. (2012) 'Propensity score matching', *The American Statistician*.

Plowman, S. (1995) 'Engaging reflexivity and positionality: qualitative research on female single parents and residential location choice', *New Zealand Geographer*, 51(1), pp. 19-21.

Poortinga, W., Dunstan, F.D. and Fone, D.L. (2008) 'Neighbourhood deprivation and self-rated health: the role of perceptions of the neighbourhood and of housing problems', *Health & place*, 14(3), pp. 562-575.

Prata, N. *et al.* (2011) 'Provision of injectable contraceptives in Ethiopia through community-based reproductive health agents', *Bulletin of the World Health Organization*, 89, pp. 556-564.

Rabe-Hesketh, S. and Skrondal, A. (2002) 'Estimating Chopit Models in GLLAMM', *London: Department of Biostatistics and Computing, Institute of Psychiatry, King's College, University of London*.

List of References

Rahman, M.S. (2017) 'The Advantages and Disadvantages of Using Qualitative and Quantitative Approaches and Methods in Language" Testing and Assessment" Research: A Literature Review', *Journal of Education and Learning*, 6(1), pp. 102-112.

Rao, A.K. *et al.* (2009) 'Clinical measurement of mobility and balance impairments in Huntington's disease: validity and responsiveness', *Gait & posture*, 29(3), pp. 433-436.

Razali, S., Khan, U. and Hasanah, C. (1996) 'Belief in supernatural causes of mental illness among Malay patients: impact on treatment', *Acta psychiatrica scandinavica*, 94(4), pp. 229-233.

Redshaw, M. *et al.* (2013) 'Women with disability: the experience of maternity care during pregnancy, labour and birth and the postnatal period', *BMC pregnancy and childbirth*, 13(1), p. 174.

Reeve, B.B. and Fayers, P. (2005) 'Applying item response theory modeling for evaluating questionnaire item and scale properties', *Assessing quality of life in clinical trials: methods of practice*, 2, pp. 55-73.

Renssen, R.H. (1998) 'Use of statistical matching techniques in calibration estimation', *Survey Methodology*, 24, pp. 171-184.

Reynolds, H.T. (1984) *Analysis of nominal data*. Sage.

Rice, N., Robone, S. and Smith, P. (2011) 'Analysis of the validity of the vignette approach to correct for heterogeneity in reporting health system responsiveness', *The European Journal of Health Economics*, 12(2), pp. 141-162.

Richards, T. (2002) 'An intellectual history of NUD* IST and NVivo', *International Journal of Social Research Methodology*, 5(3), pp. 199-214.

Rubin, D.B. (1986) 'Statistical matching using file concatenation with adjusted weights and multiple imputations', *Journal of Business & Economic Statistics*, 4(1), pp. 87-94.

Rusinga, O. (2012) 'Perceptions of deaf youth about their vulnerability to sexual and reproductive health problems in Masvingo District, Zimbabwe', *African journal of reproductive health*, 16(2), pp. 271-282.

Rutstein, S.O. and Rojas, G. (2006) 'Guide to DHS statistics', *Calverton, MD: ORC Macro*.

Sabariego, C. (2017) *Model Disability Survey*. Available at: https://www.icf-research-branch.org/other-research-programs-and-projects/model-disability-survey-mds (Accessed: 29 July 2019).

Sabariego, C. *et al.* (2015) 'Measuring disability: Comparing the impact of two data collection approaches on disability rates', *International journal of environmental research and public health*, 12(9), pp. 10329-10351.

Salomon, J.A. *et al.* (2003) 'Quantifying individual levels of health: definitions, concepts and measurement issues', *Health Systems Performance Assessment: Debate, Methods, and Empiricism*, pp. 301-18.

Salomon, J.A., Tandon, A. and Murray, C.J. (2001) 'Using vignettes to improve cross-population comparability of health surveys: concepts, design, and evaluation techniques', *Global Programme on Evidence for Health Policy Discussion Paper*, 41.

Salomon, J.A., Tandon, A. and Murray, C.J. (2004) 'Comparability of self rated health: cross sectional multi-country survey using anchoring vignettes', *Bmj*, 328(7434), p. 258.

Schmidt, C.W. (2007) 'Environmental connections: a deeper look into mental illness', *Environmental Health Perspectives*, 115(8), p. A404.

Schnittker, J., Freese, J. and Powell, B. (2000) 'Nature, nurture, neither, nor: Black-White differences in beliefs about the causes and appropriate treatment of mental illness', *Social Forces*, 78(3), pp. 1101-1132.

Sen, A. (2002) 'Health: perception versus observation: self reported morbidity has severe limitations and can be extremely misleading'. British Medical Journal Publishing Group.

Servais, L. *et al.* (2002) 'Contraception of women with intellectual disability: prevalence and determinants', *Journal of Intellectual Disability Research*, 46(2), pp. 108-119.

Shakespeare, T. (2000) 'Disabled sexuality: toward rights and recognition', *Sexuality and disability*, 18(3), pp. 159-166.

Shakespeare, T. (2013) *Disability rights and wrongs revisited*. Routledge.

Shakespeare, T., Iezzoni, L.I. and Groce, N.E. (2009) 'Disability and the training of health professionals', *The Lancet*, 374(9704), pp. 1815-1816.

Simonson, J., Gordo, L.R. and Kelle, N. (2012) 'Statistical Matching of the German Aging Survey and the Sample of Active Pension Accounts as a Source for Analyzing Life Courses and Old Age Incomes', *Historical Social Research/Historische Sozialforschung*, pp. 185-210.

Singh, S. *et al.* (2003) 'Adding it up. The benefits of investing in sexual and reproductive health care'.

Slikker, J. (2009) 'Attitudes towards persons with disability in Ghana', *VSO, Sharing skills, Changing Lives, Ghana Volunteer May*.

Smith, E. *et al.* (2004) 'Barriers to accessing safe motherhood and reproductive health services: the situation of women with disabilities in Lusaka, Zambia', *Disability and rehabilitation*, 26(2), pp. 121-127.

Spence, N.J. (2008) 'The long-term consequences of childbearing physical and psychological well-being of mothers in later life', *Research on Aging*, 30(6), pp. 722-751.

Sperandei, S. (2014) 'Understanding logistic regression analysis', *Biochemia medica: Biochemia medica*, 24(1), pp. 12-18.

Srivastava, P. and Hopwood, N. (2009) 'A practical iterative framework for qualitative data analysis', *International journal of qualitative methods*, 8(1), pp. 76-84.

Stahl, S.T. and Patrick, J.H. (2011) 'Perceived functional limitation and health promotion during mid-to late life: The mediating role of affect', *The New School Psychology Bulletin*, 8(2), pp. 26-33.

Steiner, W.A. *et al.* (2002) 'Use of the ICF model as a clinical problem-solving tool in physical therapy and rehabilitation medicine', *Physical therapy*, 82(11), pp. 1098-1107.

Stephen Thompson (2017) *Disability prevalence and trends. K4D Helpdesk Report,*. Brighton, UK.

Stone-MacDonald, A. and Butera, G.D. (2014) 'Cultural beliefs and attitudes about disability in East Africa', *Review of Disability Studies: An International Journal*, 8(1).

Stöpler, L. (2007) *Hidden Shame: Violence against children with disabilities in East Africa*. Stichting Terre des hommes Nederland.

List of References

Sultana, F. (2007) 'Reflexivity, positionality and participatory ethics: Negotiating fieldwork dilemmas in international research', *ACME: An international E-journal for Critical Geographies*, 6(3), pp. 374-385.

Szwarcwald, C.L. and Viacava, F. (2005) 'World health survey in Brazil, 2003', *Cadernos de Saúde Pública*, 21, pp. S4-S5.

Tabutin, D., Schoumaker, B. and Rabenoro, M. (2004) 'The Demography of Sub-Saharan Africa from the 1950s to the 2000s', *Population*, 59(3), pp. 455-555.

Takamine, Y. (2004) *Disability issues in East Asia: Review and ways forward*. World Bank Washington, DC.

Tanabe, M. *et al.* (2015) 'Intersecting sexual and reproductive health and disability in humanitarian settings: risks, needs, and capacities of refugees with disabilities in Kenya, Nepal, and Uganda', *Sexuality and disability*, 33(4), pp. 411-427.

Tandon, A. *et al.* (2003) 'Statistical models for enhancing cross-population comparability', *Health systems performance assessment: debates, methods and empiricism. Geneva: World Health Organization*, pp. 727-46.

Tareque, M.I. *et al.* (2016) 'Is adjustment for reporting heterogeneity necessary in sleep disorders? results from the Japanese World Health Survey', *BMC psychiatry*, 16(1), p. 25.

Tavakol, M. and Dennick, R. (2011) 'Making sense of Cronbach's alpha', *International journal of medical education*, 2, p. 53.

Terzi, L. (2005) 'Beyond the dilemma of difference: The capability approach to disability and special educational needs', *Journal of philosophy of education*, 39(3), pp. 443-459.

Trochim, W.M. and Donnelly, J.P. (2001) 'Research methods knowledge base'.

Udedi, M. (2016) 'Improving Access to Mental Health Services in Malawi'. Lilongwe.

UNDP, F.g. (1997) *Fiji poverty report*. Fiji: UNDP. Available at: https://catalogue.nla.gov.au/Record/3018409.

UNFPA (2014) *1994 International Conference on Population and Development Programme of Action*. New York: UNFPA, . Available at: https://www.unfpa.org/sites/default/files/pub-pdf/programme_of_action_Web%20ENGLISH.pdf.

UNHRBA (2017) *What is a human rights based approach*. Available at: http://hrbaportal.org/faq/what-is-a-human-rights-based-approach (Accessed: 10 February 2018).

United Nations (1983) *World Programme of Action Concerning Disabled Persons*. New York: United Nations. Available at: http://disability-studies.leeds.ac.uk/files/library/united-nations-world-programme.pdf.

United Nations (1990) 'Disability statistics Compendium' (Nations, U. New York: United Nations. Available at: https://unstats.un.org/unsd/publication/seriesy/seriesy_4e.pdf.

United Nations (1994) *The standard rules on the equalization of opportunities for persons with disabilities*. United Nations.

United Nations (2015a) *Sustainable devlopment goals,*. Available at: https://sustainabledevelopment.un.org/?menu=1300 (Accessed: 01 September 2016).

United Nations (2015b) *World Population Ageing,*. United Nations. Available at:
https://www.un.org/en/development/desa/population/publications/pdf/ageing/WPA2015_Repo
rt.pdf.

United Nations (2016) *Toolkit on Disability for Africa: Culture, beliefs and disability*. Geneva:
United Nations. Available at:
http://www.un.org/esa/socdev/documents/disability/Toolkit/Cultures-Beliefs-Disability.pdf.

United Nations (2017) *Human Functioning and disability*. Available at:
https://unstats.un.org/unsd/demographic/sconcerns/disability/disform.asp?studyid=120
(Accessed: 09 March).

United Nations Human Rights Commission (2012) *The convention on the Rights of Persons with
Disabilities: Training Guide*. New York and Geneva: United Nations. Available at:
http://www.ohchr.org/EN/Issues/Disability/Pages/TrainingmaterialCRPDConvention_OptionalPro
tocol.aspx.

Üstun, T. *et al.* (2005) 'Quality assurance in surveys: standards, guidelines and procedures',
Household sample surveys in developing and transition countries, pp. 199-230.

Üstün, T.B. (2010) *Measuring health and disability: manual for WHO disability assessment
schedule WHODAS 2.0*. World Health Organization.

Üstün, T.B. *et al.* (2010) 'Developing the World Health Organization disability assessment schedule
2.0', *Bulletin of the World Health Organization*, 88(11), pp. 815-823.

Üstün, T.B. *et al.* (2003) 'The world health surveys', *Health systems performance assessment:
debates, methods and empiricism. Geneva, World Health Organization*, 797.

Üstün, T.B. *et al.* (2001) 'WHO multi-country survey study on health and responsiveness', *Geneva:
World Health Organization*.

van der Linden, W.J. and Hambleton, R.K. (2013) *Handbook of modern item response theory*.
Springer Science & Business Media.

Van Rooy, G. and Mufune, P. (2014) 'Experiences and perceptions of HIV/AIDS and sex among
people with disabilities in Windhoek, Namibia', *Sexuality and Disability*, 32(3), pp. 311-321.

Vaughan, C. *et al.* (2015) 'W-DARE: a three-year program of participatory action research to
improve the sexual and reproductive health of women with disabilities in the Philippines', *BMC
public health*, 15(1), p. 984.

Verbrugge, L.M. (1985) 'Gender and health: an update on hypotheses and evidence', *Journal of
health and social behavior*, pp. 156-182.

Verbrugge, L.M. and Jette, A.M. (1994) 'The disablement process', *Social science & medicine*,
38(1), pp. 1-14.

Vigo, D., Thornicroft, G. and Atun, R. (2016) 'Estimating the true global burden of mental illness',
The Lancet Psychiatry, 3(2), pp. 171-178.

Wan, N. (2003) ''Orange in a World of Apples': The voices of albinism', *Disability & Society*, 18(3),
pp. 277-296.

Wand, J., King, G. and Lau, O. (2011) 'Anchors: Software for anchoring vignette data', *Journal of
Statistical Software. Forthcoming, URL http://www. jstatsoft. org*.

Ware Jr, J.E. (2000) 'SF-36 health survey update', *Spine*, 25(24), pp. 3130-3139.

List of References

Washington Group on Disability Statistics (WG) (2008) *Development of an Internationally Comparable Disability Measure for Censuses*. New York. Available at: http://www.cdc.gov/nchs/washington_group/wg_meeting3.htm#papers.

Wazakili, M., Mpofu, R. and Devlieger, P. (2006) 'Experiences and perceptions of sexuality and HIV/AIDS among young people with physical disabilities in a South African township: a case study', *Sexuality and Disability*, 24(2), pp. 77-88.

Weber, R. and Weber, D. (2013) *Statistical matching of EU-SILC and the Household Budget Survey to compare poverty estimates using income, expenditures and material deprivation*.

Wegner, L. and Rhoda, A. (2015) 'The influence of cultural beliefs on the utilisation of rehabilitation services in a rural South African context: therapists' perspective', *African journal of disability*, 4(1), pp. 1-8.

Wells, K.B. *et al.* (1989) 'The functioning and well-being of depressed patients: results from the Medical Outcomes Study', *Jama*, 262(7), pp. 914-919.

Welner, S. (1996) 'Contraception, sexually transmitted diseases, and menopause', *Women with physical disabilities*, pp. 81-91.

Welner, S.L. (1999) 'Contraceptive choices for women with disabilities', *Sexuality and disability*, 17(3), pp. 209-214.

Wen, M., Hawkley, L.C. and Cacioppo, J.T. (2006) 'Objective and perceived neighborhood environment, individual SES and psychosocial factors, and self-rated health: An analysis of older adults in Cook County, Illinois', *Social science & medicine*, 63(10), pp. 2575-2590.

Wheaton, F.V. and Crimmins, E.M. (2016) 'Female disability disadvantage: a global perspective on sex differences in physical function and disability', *Ageing & Society*, 36(6), pp. 1136-1156.

Whiteford, H.A. *et al.* (2013) 'Global burden of disease attributable to mental and substance use disorders: findings from the Global Burden of Disease Study 2010', *The Lancet*, 382(9904), pp. 1575-1586.

Whitehead, S.J. and Ali, S. (2010) 'Health outcomes in economic evaluation: the QALY and utilities', *British medical bulletin*, 96(1), pp. 5-21.

Whiteneck, G. (2006) *Workshop on disability in America: A new look*. The National Academies Press Washington DC.

Whiteneck, G. *et al.* (2004) 'Environmental factors and their role in participation and life satisfaction after spinal cord injury1', *Archives of physical medicine and rehabilitation*, 85(11), pp. 1793-1803.

Whiteneck, G.G., Gerhart, K.A. and Cusick, C.P. (2004) 'Identifying environmental factors that influence the outcomes of people with traumatic brain injury', *The Journal of head trauma rehabilitation*, 19(3), pp. 191-204.

WHO and World Bank Group (2011) *World report on disability*. Geneva, Switzerland World Health Organization.

WHO and CBM (2013) *Millions of people in the World have hearing loss that can be treated or prevented,*. Geneva. Available at: https://www.who.int/pbd/deafness/news/Millionslivewithhearingloss.pdf.

WHO and UNFPA (2009) 'Promoting sexual and reproductive health for persons with disabilities: WH'.

Witvliet, M. (2014) 'World health survey: a useful yet underutilized global health data source', *Austin J Public Health Epidemiol*, 1(3), p. 1012.

Wong, L.P. (2008) 'Focus group discussion: a tool for health and medical research', *Singapore Med J*, 49(3), pp. 256-60.

Wood, S. (2010) 'Sexual and reproductive health for all. Reducing poverty advancing development and protecting human rights'.

World Health Organization (1980) *International Classification of Impairements, Disabilities and Handicaps*. Geneva: WHO. Available at: http://apps.who.int/iris/bitstream/10665/41003/1/9241541261_eng.pdf.

World Health Organization (2001) *International Classification of Functioning, Disability and Health: ICF*.

World Health Organization (2002) *Towards a common language for functioning, disability and health: ICF*. World Health Organisation.

World Health Organization (2003) *World Health Survey 2003: Malawi Report*. Geneva, Switzerland: Organization, W.H. Available at: http://www.who.int/healthinfo/survey/whsmwi-malawi.pdf.

World Health Organization (2011) *World report on disability*. World Health Organization.

World Health Organization (2015a) *WHO global disability action plan 2014-2021: Better health for all people with disability*. World Health Organization.

World Health Organization (2015b) *World Health Survey (WHS)*. Available at: http://apps.who.int/healthinfo/systems/surveydata/index.php/catalog/whs/about (Accessed: 15/01/2016).

World Health Organization (2017) *Mental disoders*. Available at: http://www.who.int/mediacentre/factsheets/fs396/en/ (Accessed: 06 April).

World Health Organization (2019) 'Model Disability Survey: Providing evidence for accountability and decision-making'. Available at: https://www.who.int/disabilities/data/mds_v4.pdf?ua=1 (Accessed: 29 July 2019).

Wu, C. (2003) 'Optimal calibration estimators in survey sampling', *Biometrika*, 90(4), pp. 937-951.

Yang, F.M. (2014) 'Item response theory for measurement validity', *Shanghai archives of psychiatry*, 26(3), p. 171.

Yousafzai, A.K. *et al.* (2004) 'Knowledge, personal risk and experiences of HIV/AIDS among people with disabilities in Swaziland', *International journal of rehabilitation research*, 27(3), pp. 247-251.

Zamawe, F.C. (2015) 'The implication of using NVivo software in qualitative data analysis: Evidence-based reflections', *Malawi Medical Journal*, 27(1), pp. 13-15.

Zar, J.H. (1998) 'Spearman rank correlation', *Encyclopedia of Biostatistics*.

Zhang, L.-C. (2015) 'On Proxy Variables and Categorical Data Fusion', *Journal of Official Statistics*, 31(4), pp. 783-807.

Zhang, W. *et al.* (2010) 'Education and self-rated health: an individual and neighborhood level analysis of Asian Americans, Hawaiians, and Caucasians in Hawaii', *Social science & medicine*, 70(4), pp. 561-569.

List of References

Zimbabwe Ministry of Health (2013) *Living Conditions among Persons with Disabilities Survey*. Zimbabwe: Ministry of Health. Available at: https://www.unicef.org/zimbabwe/National_Survey_on_Disability_2013(1).pdf.